DOCTOR OF EDUCATIONAL PSYCHOLOGY

Understanding the Development of Young Children with Complex Additional Support Needs

Rees, Kirstie

Award date:
2020

DOCTORATE IN EDUCATIONAL PSYCHOLOGY

Understanding the Development of Young Children With Complex Additional Support Needs

Kirstie Rees

2020

University of Dundee

ABSTRACT

This thesis presents a body of work for the award of the Professional Doctorate in Educational Psychology. It is comprised of two projects and a literature review, all of which are united by a broad interest in supporting children with complex additional support needs[1] and by a specific interest in in exploring conceptualisations of development for this group of learners. The aim of the thesis is to inform an understanding of development that is shared by both parents and education staff and which leads to the identification of meaningful targets and strategies to promote a child's progress, supported by educational psychology practice.

Project I consists of a Recognised Prior Learning claim (RPL) for 20% of the award (Appendix 2). The claim details the process leading to the development of the South Lanarkshire Framework (South Lanarkshire Inclusion and Psychological Service, 2015) for supporting pupils with complex additional support needs (referred to throughout as 'The Framework'). This document contains information about how children with this level of need learn and provides advice about appropriate assessment and teaching approaches. The RPL claim also contains an article detailing the development, implementation and evaluation of The Framework (Rees, Tully & Ferguson, 2017). This evaluation, involving seven Additional Support Needs establishments and using a pre and post audit of curricular practice and semi-structured interviews, emphasises the positive impact of The Framework on teacher practice and mind-set. The findings also highlight the need to further clarify parents' and education staff definitions of progress. This paved the way for the literature review and Project II.

The literature review begins by considering dominant theories of development in relation to the progress of children with complex additional support needs. Consideration is also given to how categorisations of disabilities and definitions of educational needs are dependent upon the educational and legislative context of the time. Dominant models of disability are also explored. In accordance with the ecological model of development underpinning current educational

[1] The descriptor 'complex additional support needs' is used both in the Doran Review (Scottish Government, 2012) and the Milestones document (Education Scotland, 2019) This is described as a 'working description' (not definition) of a child or young person who has additional support needs arising from one or more complex factors or multiple factors that are likely to continue for more than a year.

psychology practice, the literature review employs the transactional model of development (Sameroff and Fiese, 2000) and also the cultural historical model (Bøttcher and Dammeyer, 2016) as a framework to explore teachers' and parents' conceptualisations of development of young children with complex additional support needs. This permits further analysis of the impact of societal influences, models of disability and organised practice on beliefs and responses to individual children. It also includes further consideration of the literature which focuses on the extent to which a child's presentation informs adult-child interaction.

Connecting with the above themes, the final and most substantial project, Project II, uses qualitative methodology and Interpretative Phenomenological Analysis (IPA) to explore parents' and nursery staff conceptualisations of the development of young children with complex additional support needs. Views are obtained from individual interviews and from two focus groups involving both sets of participants. The main themes emerging from the data indicate that how progress is perceived is very much influenced by cultural norms and by the extent to which those supporting a child adhere to a linear trajectory of progress and are subject to existing power differentials. Other mediating factors such as a child's aetiology and presentation are also considered. The detail and implications of the findings and research are discussed and explored. This includes consideration of a broader ecological approach to understanding development which aids nursery staff and parents to better comprehend the societal, environmental and relational factors informing individual understandings of the development. This then enables professionals to identify why, at times, there may be a mismatch between parents' and education staff views and to address this openly and explicitly, whilst aiming to reduce power differentials.

DEDICATION

To my husband, Gareth, and my two daughters, Daisy and Madeline, for all their love, patience and support.

In memory of Thomas, who brought this thesis into being.

ACKNOWLEDGEMENTS

I firstly thank my two supervisors, Richard Ingram and Sarah Hulme, for their ongoing guidance, support and constructive questioning. Our three-way dialogue inspired me to consider the research from a more philosophical stance and to continue to read and learn throughout the process. The supervision sessions always passed way too quickly, and I left each time with a renewed sense of motivation. I will miss my journeys to Dundee.

The studies referred to in this thesis were conducted when I was employed as a senior educational psychologist in South Lanarkshire. I feel very thankful for the opportunities afforded to me by South Lanarkshire Psychological Service, and the ongoing support and encouragement of the Principal Educational Psychologist, Elizabeth King. Elizabeth recognised and nurtured my interest in this area of work and allowed me to take forward the research at an authority level. A special gratitude is also extended to Nick Smiley, the Principal Educational Psychologist in East Renfrewshire where I am now employed. His continued support has enabled me to complete the Doctorate and to consider ways in which the contents can be applied to our practice.

Most of all, I am grateful to the families and nursery staff from whom I learned a great deal. Thank you for being open and for sharing such rich accounts of your experiences.

SIGNED DECLARATION

I hereby declare that the candidate is the author of the thesis; that, unless otherwise stated, all references cited have been consulted by the candidate; that the work of which the thesis is a record has been done by the candidate, and that it has not been previously accepted for a higher degree

[redacted] **Date:** 2.3.20

Table of Contents

LIST OF TABLES/DIAGRAMS

TABLES

DIAGRAMS

CHAPTER 1

INTRODUCTION TO THESIS

1.1 Introduction

How do we best support the progress of children with complex additional support needs? Teaching practice in this area is fraught with tensions; there have been repeated attempts to provide a definition for this group of learners; to promote inclusive practice (without always possessing an operational definition of the term) and to implement a curriculum which advocates that all children should access to the same learning experiences. At the same time, parents with young children with complex additional support needs may struggle to make sense of their child's development and to interpret the views imparted by a number of professionals, each with their own professional ideology. This sense of confusion is further exacerbated by the challenge that their child's disability poses to common parental expectations and to deeply engrained beliefs about the trajectory of a child's life. This is an area under researched.

This thesis starts with the premise that to promote the progress of children with complex additional support needs, we must first explore conceptualisations of a child's development. This requires an understanding of a child's aetiology, whilst at the same being cognisant of the impact of ecological factors on the child's development. Significantly, this also requires an exploration of cultural norms about progress.

The work contained within the thesis follows my own professional and doctoral journey; starting with an attempt at an authority level to increase the knowledge and skills of education staff and expanding in scope and depth, to explore parents' and nursery staff views about a young child's development and how these conflict and converge. The continual search for knowledge, reflected by both parents and staff, is exacerbated by the emotional impact of parenting a child out with what is considered to be the norm.

What emerges from the research is the need for educational psychologists to support interventions that enable education staff to integrate the perspectives of parents into their understandings and to reflect upon the influence of wider cultural norms on how we understand the development of children with complex additional support needs. This thesis does not suggest that such norms can easily be challenged but proposes that by making them explicit, we can consider the extent to which they influence policy, pedagogy and individual approaches to supporting children. Ensuring positive developmental conditions for children with this level of need thus requires ongoing constructive dialogue between parents and education staff which educational psychologists are well positioned to support. The ultimate aim of the research is to elicit ways of creating a shared understanding of progress – one which will facilitate the identification of meaningful targets and teaching approaches which ensure that that the progress of a child with complex additional support

needs is identified and celebrated. Developmental trajectories are not deemed to be inevitable, therefore, but are viewed instead as being informed by children, parents and their teachers.

1.1.1 Structure of Contents

This thesis presents a body of work for the award of the Professional Doctorate in Educational Psychology and is comprised of a literature review and two research studies. The three distinct pieces of work reflect my personal and professional interest in the development of children with complex additional support needs and follow my evolvement as an educational psychologist and researcher in this area of study. Whilst the literature review and Project II were completed when I was a Doctoral student, the first project was conducted over a three-and-a-half-year period when I was in post as a senior educational psychologist in South Lanarkshire. This work is presented as a Request for Prior Learning Claim (RPL) and is contained within Appendix 2. This provided the springboard for the subsequent research.

This thesis is organised into five chapters, the structure and contents of which are detailed below.

1.1.2 Chapter 1

Chapter 1 presents an introduction to the thesis. The structure, motivations and aims of the research are explained and further detail about the chosen methodology is provided, informed by the underpinning social constructionist epistemology.

1.1.3 Chapter 2 Literature Review

This section explores prevalent theories of child development and other research which has informed understandings of the development of children with complex additional support needs. This is set within the context of both historic and current educational policy and legislation in relation to children and young people with complex additional support needs. The literature review also includes analysis of the use of categorisations and descriptors which aim to highlight the needs of this group of learners. This then paves the way for further exploration of models of disability and different ecological models of development which demonstrate the extent to which the trajectory of a disabled child's development is shaped by the environment and wider cultural factors. The transactional model of development (Sameroff and Fiese, 2000) and also the cultural historical model (Bøttcher, and Dammeyer, 2016), are then employed as a framework to explore parent and teacher conceptualisations of development. This includes an analysis of the literature which focuses on adult-child interaction and which explores teaching and assessment approaches, and attitudes to inclusion. The literature also suggests joint interventions for children with complex additional support needs.

1.1.4 Chapter 3 Project II

Chapter 3 contains a description of the qualitative research undertaken, detailing the sample selection and qualitative methodology. Interpretative Phenomenological Analysis is used to explore how parents' interpretations of their child's development conflict and converge with those of nursery staff and with dominant narratives of disability. In addition to the analysis of individual interviews, two focus groups are employed to discuss and confirm or disconfirm themes which have emerged from the interview data. Five over-arching themes emerge from the analysis; one of which is considered as an 'overarching' theme since it highlights the influence of dominant cultural norms and subsequent power differentials on participants' conceptualisations of development. Under the title of each theme, a table summarises the number of examples of each of the subthemes elicited from the data. This is then followed by in-depth analysis**.**

1.1.5 Chapter 4 Conclusion

This chapter provides further reflection on the chosen sample and methods of data analysis, in addition to the limitations of the study. There is a summary of the main findings of the study and consideration of how these can be used to build capacity amongst those supporting the development of young children with complex additional support needs. This includes making nursery staff and parents aware of the impact of cultural norms on views of progress and using tools such as the questionnaire employed as part of the study to make individual views explicit. Further consideration is also given to how a broader ecological approach accords with a biopsychosocial model and can inform both assessment and intervention approaches. There is also a fuller discussion about a proposed joint intervention which aims to reduce power differentials between nursery staff and parents, and which focuses on establishing a shared view of progress. Ultimately, the study's findings suggest that a shared understanding will lead to a joined-up approach to supporting development and will lead to more examples of progress being noted by both parents and nursery staff. The conclusions of the thesis are summarised, with a renewed focus on the main drivers behind the research and the implications for educational psychology practice.

1.1.6 Appendices

Project one comprises a recognised prior learning claim (RPL) for 20% of the award. This section presents one academic paper published in a peer-reviewed (Rees, Tully and Ferguson, 2017) and a conference presentation (Rees, 2016). The papers are accompanied by a reflective narrative that connects the papers with the level twelve outcome standards as set out in the Scottish Credit and Qualifications Framework (2007). The narrative describes the development, implementation and evaluation of the South Lanarkshire Framework for supporting pupils with complex additional

support needs (South Lanarkshire Psychological and Inclusion Service, 2015) and details where and how the SCQF criteria are met.

1.2 Ontology and Epistemology

The structure and contents are underpinned by my own ontological and epistemological beliefs, which have been informed by both professional and personal experiences. For me, my role as a researcher is intertwined with my roles in other social contexts.

As an educational psychologist, my practice and professional ideology are largely underpinned by social constructionism. Social constructionism has arisen from and is influenced by a variety of disciplines, thus making its interpretations very broad. When used ontologically, the term social constructionism refers to the way in which real phenomenon, our perceptions and experiences are brought into existence and take the particular form that they do as a result of the context and the language that we use (Berger and Luckman, 1966). Social constructionism thus provides an epistemological framework which examines how meaning and reality are socially constructed through our interactions and discourse amongst individuals and groups (Robson and McCartan, 2016).

Educational psychology's adoption of social constructionism as an overarching theory to inform practice was marked by the publication of Bill Gillham's 'Reconstructing Educational Psychology' (Gillham, 1978) and signified a move away from within child-approaches to practice and positivist approaches to research. Instead, educational psychology practice began to draw on theories derived from social constructionism. For example, Bronfenbrenner's ecological theory (1994), which underpins current educational psychology, draws on complex social transactional theory and highlights the different contextual influences on a child's development. This emphasises the importance of using multiple methods of assessment to obtain a plurality of perspectives and has promoted practice which endorses interventions at the level of the child, family and school. As such, educational psychologists have become more involved in attempting to influence processes at a systemic level.

Social constructionism also provides an important counterpoint to medicine's largely deterministic approaches to illness and disability by exploring the ways in which our understanding of disability and definitions of a child's additional support needs are very much dependent upon the discourses that are culturally available at that time. Since the 1970s, there has been an increase in social constructionist research on the distinction between biological impairment and the social meaning of the condition. Friedson (1970) highlighted that the way in which symptoms are labelled,

diagnosed and then understood are social constructions, based on social ideas about what is acceptable and about what is not (Coburn, 1992). This paved the way for Foucault (2019), whose writings contributed significantly to a social construction of disability by postulating knowledge as a form of power. Importantly, he argued that expert knowledge about human "normality" and "abnormality," which is not objective or naturally given, is the principal form of power in modern societies. Thus, 'disability', a term which is particularly embedded within cultural meanings of 'abnormal', is associated with language which describes it as such. This in turn influences people's responses, impacts upon their subjective experiences of embodiment, shapes their identities, and influences the interventions implemented. It also informs wider societal and educational decisions about how children's needs should be met.

Attitudes towards learners with complex additional support needs are therefore largely influenced by the current political and social context and by prevalent models of disability which may hold more currency in different environments. As an educational psychologist, the adoption of a social constructionist approach places emphasis on working with others in ways to accept and validate different people's interpretation of a child's progress. Using research methods to obtain multiple perspectives has been of significant importance in my role as an educational psychologist when working with learners who do not adhere to what are perceived to be developmental norms. In such a context, it is more probable that different practitioners or parents construct their own unique version of their child's performance or development which they may consider to be more accurate than those of other people.

However, although educational psychology has endorsed social constructionism both at an ideological level and in practice, the profession has struggled more to apply its principles to research. According to Kelly (2006), this is because the processes which educational psychologists seek to evaluate - namely educational interventions at the level of the child, school and authority - are often *'fluid, negotiable, subject to interpretation, without firm evidence, and inevitably vulnerable to social controls and power differentials'* (Kelly, 2006, p58). This has made research more 'unwieldy' and at odds with current government educational policy which continues to promote the use of quantitative data as a means of evaluating the effectiveness of educational interventions. In addition, a social constructionist approach may seem incongruous when the population which forms the basis of my research are largely non-verbal and do not have recourse to language as a means of interpreting their experience.

Despite the fact that there is a view that most social constructionists view language as the only reality, this is contradicted by Edley (2001) and Burr (2015), both of whom do not contest

phenomena as being unreal, but rather how they are interpreted as being the product of social constructionism. Snail describes language as articulating our experience '*as best we can'* (Smail, 2005; p91). According to the author, although ultimate reality remains beyond our grasp, this does not mean there is no such thing as reality. Reality is sensed in embodied experience before it is articulated in words. Indeed, for children with very complex additional support needs, this may be the only way that they make sense of their experience. This interpretation of social constructionism (and one with which I concur) does not deny the existence of 'real' phenomena out with language, nor suppose that language may always be the only means by which we make sense of the world. Thus, a child may have a biological impairment but how this is understood is constructed socially and through interaction between child, parents and professionals and how they live with this. Instead, a fuller exploration of a child's diagnosis or syndrome, in conjunction with an analysis of the impact of societal factors on those supporting the child, will lead to a fuller understanding of a child's development.

These more recent reformulations of social constructionism have attempted to combine methods from positivism and relativism (Willig, 2012). Elder-Vass (2012) argues for a 'realist' social constructionism where the social constructionism involved is moderate, rather than radical or strong, and allows for the reality of some things as existing and having causal effects interdependently of human thought and language. He proposes that what people believe to be real is significantly shaped not only by objective reality but also by their socio-cultural contexts. This makes use of both qualitative and quantitative methods to inform assessment and evaluation. Indeed, the study which makes up the RPL component of the Doctorate (Appendix 2) adopts a 'critical realist 'approach (Kelly, Woolfson and Boyle, 2008); set within a Scottish local authority context, it employs both qualitative and quantitative data as a means of evaluating the impact of a new South Lanarkshire Framework for supporting pupils with complex additional support needs on staff practice (Rees, Tully and Ferguson, 2017). The use of a pre and post audit of curricular practice and a staff questionnaire about the impact of The Framework is triangulated with analyses of semi structured interviews.

However, it was the qualitative data obtained from this study – richer and more diverse in terms of its contents - which informed the contents of the literature review. This second study provides a more wholescale adoption of a social constructionist methodology, seeking to understand parents' and nursery staff beliefs about the development of nursery aged children with complex additional support needs and therefore employing a qualitative methodology which enables further analysis of individual lived experiences. The use of a method which affords importance to language

and its interpretation was deemed especially important when considering the views of parents and nursery staff. In an environment where local and national policy continue to value quantitative data, the intent is to show that qualitative research can be used successfully to contribute to psychological theory and inform educational psychology practice. As an educational psychologist, therefore, I am also a pragmatist (Garrison, 1998);- the context within which I work - both political and pedagogical - necessitates a more flexible approach to research based upon a careful consideration of methods that will best fit with the aims of the research and that will be the most impactful in the educational context of the time. Indeed, this awareness of the wider context is reflective of my moderate social constructionist epistemology and ontology.

Interwoven within my professional values and practice are my experiences and feelings as a mother of a son with cerebral palsy. For me, it is impossible to conduct research in this sector without acknowledging the extent to which my own personal experience is at the core of my intellectual interest in exploring conceptualisations of development for children with complex additional support needs and of others' lived experiences of doing so. During my son's life, I grappled to understand what the primary focus should be in terms of supporting his progress; what I should be doing in order to facilitate my interaction with him and to help promote his development. At the same time, I battled against my feelings of inadequacy and guilt as a mother, since despite our support and previous experience, my son could not attain the 'milestones' which my daughter had superseded effortlessly. When my son smiled at the age of four months, I wanted to sing it from the rooftops.

As a psychologist, I became invested in supporting others to define and address the educational needs of children with complex additional support needs. I have also become increasingly aware of the differing views - especially between parents, professionals and teaching staff. Much of the role as an educational psychologist can be to make such perspectives explicit, as a means of searching for common ground. Yet still, in such situations, both the curriculum and other cultural pressures can exacerbate already confusing conversations about defining educational needs and determining how they should be addressed

The second research study, Project II, thus brings together both my experience as an educational psychologist and as a mother. I am aware that my own experience undoubtedly informs my analyses of the accounts of mothers with whom I emphasise; there may also be a tendency to interpret others' experiences in relation to my own, and to presume that how mothers feel about their child's development mirrors what my own feelings were towards my son. This required me to reflect more carefully and to highlight participants' diverse responses and the extent to which

my own experiences may have informed the analyses. I am also cognisant of the often unequal relationships in a parent-professional context, and within a research context. Consequently, in the second study, my research practice draws on a 'participatory' research paradigm (Guba & Lincoln, 2005) and aims to promote transparency and to increase validity, by sharing analyses with participants and attempting to explore with them the meanings that have been extrapolated from their interviews.

CHAPTER 2 LITERATURE REVIEW

An Ecological Approach to Understanding the Development of Children With Complex Additional Support Needs; Parent and Teacher Responses

2.1 Introduction

In most cultures, typical development is conceptualised as a maturational process influenced by common biological characteristics and by what are regarded as universal stages of child development (e.g. the acquisition of language and social skills; the emergence of major emotional and cognitive systems; attachment to a main caregiver. Gesell's studies of how infants grow, attain motor coordination, and learn new skills furnished the first comprehensive theory of the interrelated sequences through which infants and children pass in their physical and mental development (Ball, 1977). This led to a focus on a maturational approach to development, emphasising the set stages of development in accordance with a child's chronological age which is still very much prevalent in early years practice today. Yet the tenets of prevalent developmental theories cannot be readily applied to children with complex additional support needs, who often present with distinct and non-linear trajectories. Despite the research conducted in this field (e.g. Zigler's 2-Structure Approach, 1967; Burack, Hodapp, Iarocci & Zigler, 2012), the absence of group norms often results in practices which have been influenced more by different models of disability (medical and social) than by research. This may result in a focus on different aspects of development and on different methods of promoting progress in home and school settings.

Ecological models highlight the role of the environment in informing the development of children with complex additional support needs. In educational psychology practice, Bronfenbrenner's ecological theory (1994) underpins assessment and ensures that wider contextual factors are explored as a means of understanding the different environmental factors that inform a child's development. The transactional model of development (Sameroff & Fiese, 2000) goes one step further, highlighting the importance of individual differences and the child's presentation in terms of what a child elicits from the environment and how the environment in turn shapes his or her progress. More recently, the cultural-historical approach, proposed by Bøttcher and Dammeyer (2016), emphasises the extent to which the progress of a child is influenced by social and cultural practices. However, at the same time, cognisance is taken of the child's underlying impairment and the extent to which this contributes to a specific profile of strengths and weaknesses.

2.1.1 Literature Search

This literature review will use an ecological model, in particular the transactional model of development, as a framework for exploring parents' and teachers' conceptualisations of the development of children with complex additional support needs. This will include an analysis of how societal influences and organised practices give rise to such beliefs (e.g. models of disability; cultural assumptions about typical development; the school curriculum) and inform adult-child interactions and strategies and interventions to support the child's development. There will also be further comparison of both parent and teacher approaches to promoting the child's progress.

Given the breadth of the literature review, the search was conducted in stages and involved a review of research underpinned by diverse methodologies. I conducted a search of the literature pertaining to their development. I conducted a systematic review of the literature, using the PRISMA guidelines (Moher, Liberati, Tetzlaff & Altman, 2009), to identify relevant works. English language peer-reviewed journal articles, PhD theses, Doctorates, books and reports were included. This enabled me to conduct a broader search. I also chose to use a diverse range of terms to describe the child's learning needs – given that I was aware that categorisations change over time and in different contexts (e.g. medical and educational). The Social Sciences Citations Index, PubPsych, and Springerlink were searched using the following Boolean phrase: (development OR ((progress)AND cognitive AND complex AND (severe OR profound AND ((intellectual OR learning AND disability) OR learning disabilities) OR learning difficulties OR (severe and complex) OR ((additional support needs OR autism)). No start date was specified for the search. Literature searches were started in May 2016 and a manual search of the literature was also carried out. A snowballing method was also adopted, whereby reference lists were searched for relevant literature. I used Google Scholar to do this and the Dundee University Library search tool since I was keen to ensure that I accessed sufficient educational research and documentation.

The following criteria were applied to full-texts: involvement of children with severe or profound learning difficulties/complex additional support needs as participants - or their parents or teachers - in empirical research and articles which made clear statements regarding this group and their development. Papers were included if I believed the participants' ability met with the educational descriptor of complex additional needs. I also included research with additional needs that included a diagnosis of a disorder or syndrome which resulted in learning difficulties. Full texts were excluded if the study dealt purely with the validity or reliability of standardised instruments for diagnosis or the detection of genetic abnormalities (and were thus medical in focus).

Since the study was set within the current context of Scottish educational policy and legislation, an initial search also focused on a review of policy documents pertinent to this area. This was conducted by searching and reviewing previous documents and books that I had both read and referred to in my practice and in previous research (e.g. for the RPL claim; Appendix 2.). This was both a manual search and also a search of saved documentation, in addition to an electronic search. This also necessitated a search of historic policy and legislative documents pertinent to this sector of education and also a comparison with those which underpin practice in England. I also conducted a search of relevant journal articles which provided further reflection on policy and practice pertinent to this area and which related to educational practice in this area. I did this by accessing previously saved articles, and by then adopting a snowballing method to review other related literature.

Throughout the course of the Doctorate, I reviewed the literature in this area and kept up to date with changed in educational pedagogy and terminology. E.g. The term 'complex additional support needs', which was used initially in the Doran review (Scottish Government, 2012) was emphasised more recently in the Education Scotland 'Milestones' document (Education Scotland, 2019) which details approaches to the assessment and teaching of this group of learners. For this reason, and to set the Doctorate within the Scottish educational context at the time of writing, I chose to use this term throughout. This descriptor is also broader than the term 'severe and profound learning needs' that had been defined in The Framework (Rees, Tully & Ferguson, 2017) and encompasses better the needs of the children whose parents and nursery staff participated in Project II.

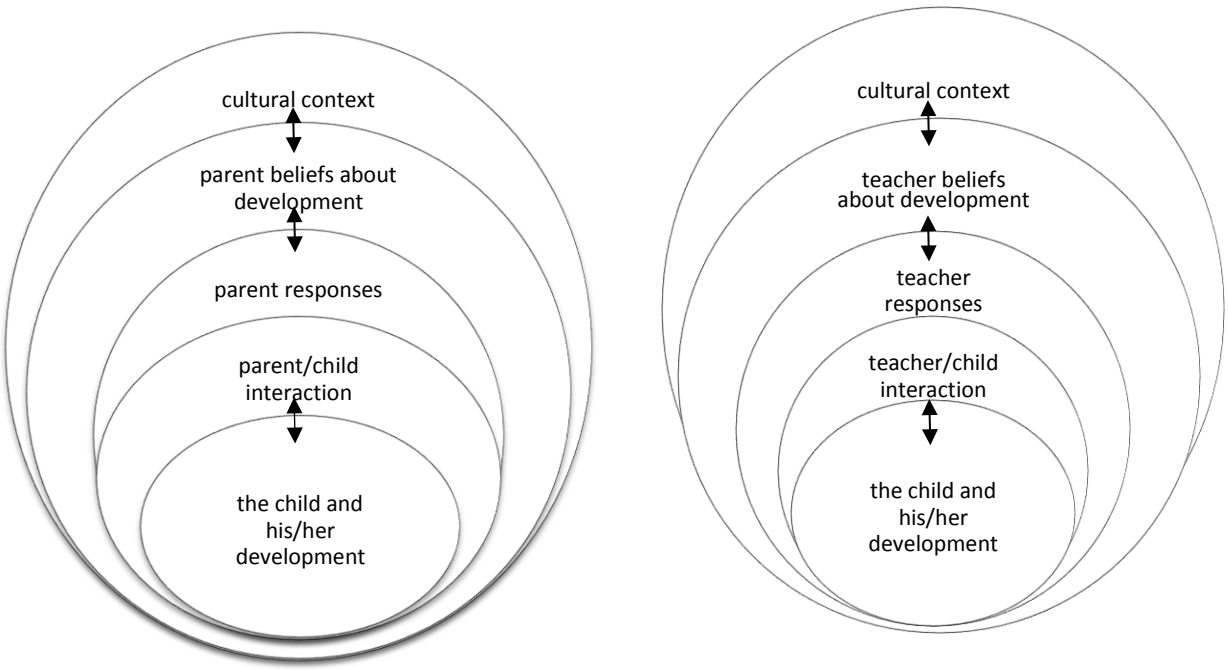
I also conducted a search of literature pertinent to educational psychology practice and conducted a manual search – referring to books and previously saved articles on ecological models of development and how these could be applied to practice as both an educational psychologist and researcher in schools;. This included re-reading 'Educational Psychology Frameworks for Practice' (Kelly, Woolfson & Boyle, 2008) and also reading and conducting an analysis of the book: 'The Development and Learning of Young Children with Disabilities' (Bøttcher &Dammeyer, 2016).

I decided to use the ecological models of development as a way of framing and conducting the remaining literature search. This involved an exploration of what little research there is on parental and education staff views of development and strategies that they use. This also necessitated an exploration of studies involving different dyads; parent-child; teacher-child; and parent-teacher and employing diverse methodologies. Given that the main aim was to explore conceptualisation of development, there was a particular focus on qualitative research which sought to encapsulate individuals' lived experience. I divided the search into two main categories; parents and then

education staff, and then further divided each of these into subcategories. E.g. for parents, this included a search of literature on views of development; strategies to promote progress; interaction with a child with a disability; resolution and insightfulness. For teachers; this included; teachers' view of development and children with complex additional support needs; views of inclusion, practice and assessment. I ensured that each subsection included studies which employed a range of methodologies. However, given that I was interested in individual views and experiences, there was a snowball effect of reading one article and finding references to another related article. Indeed, this is how I encountered the research on parental resolution. I saved each of the articles in a folder with a title (e.g. teachers' strategies and teaching practices with children with complex additional support needs.) I then re-read the articles that I had saved and created tables which highlighted the main methodologies and outcomes. These informed the final tables that are included in the literature review.

The diagram below demonstrates how the transactional model of development informs the structure of the literature review.

Diagram 1. The Transactional Model and Parent and Teacher Conceptualisations of the Development of Children with Complex additional support needs.



The research questions which informed the literature review were as follows:

1. What does research tell us about the development of children with complex additional support needs?

2. How have categorisations of disability and pedagogical policy changed over time and informed educational responses to children with complex additional support needs?

3. What are the cultural influences on parental and teacher conceptualisations of children with complex additional support needs?

4. What do parents and teachers deem to be important aspects of progress; do these differ, and do they change over time?

5. How do parental and teacher conceptualisations of development and the child's presentation inform their interaction with the child?

6. How do parents' and teachers' beliefs inform practices that they employ to promote the child's progress? Is there a focus on different aspects of development and different interventions in school and home settings?

7. If so, what interventions are currently used by parents and education staff to promote the progress of children with complex additional support needs?

2.2 The Development of Children with Complex Additional Support Needs

This section explores prevalent theories of child development and relevant research which have informed understandings of the development of children with complex additional support needs. There is further exploration of models of disability and ecological models of development which demonstrate the extent to which the trajectory of a disabled child's development is shaped by the environment and by wider cultural factors. This is then followed by information about the historical context of special education in Scotland:- how this shapes and is informed by categorisations of disability legislation and how policy informs both educational practice and the views of both parents and teachers,

In its widest sense, the term 'child development' refers to the biological, psychological and emotional changes that occur in human beings between birth and the end of adolescence, as the individual progresses from dependency to increasing autonomy. Historically, developmental theorists (e.g. Gesell; in Ball, 1977; Piaget, 1964; Selman, 1971) pursued universal truths and analysed the behaviour of the child as a means of postulating theories about internally generated changes that occur at different stages of development. Gesell was one of the first to conduct

observational studies of the sequences through which infants and children pass in their physical and cognitive development (Ball, 1977). This paved the way for the use of developmental measures as a means of measuring a young child's progress against chronological norms. Despite differences in the focus of later theorists. (E.g. cognitive development versus psychosocial development), main theories of child development continue to highlight a linear trajectory, with set sequences which are qualitatively different from the steps that preceded them (e.g. Piaget's 'sensorimotor stage' 1964; Selman's 'social informational perspective', 1971), and which are universal for typically developing children.

This has acted to produce similar developmental agendas in most cultures, particularly in the west (Sameroff & Fiese, 2000). Thus, physical milestones such as crawling and walking, or cognitive milestones such as object permanence are reported in many texts. Child development viewed in this way not only forms the basic fabric of early childhood education practice but is also the benchmark by which all children are compared. This continues, too, when children go to school; when children reach the age of five or six, it is assumed that they will be able to learn relevant social skills and cultural tools (e.g. reading and writing) which influence the development of higher cognitive functions.

Yet these universal assumptions about development do not explain pathways for all populations. For children with complex additional support needs, the assumptions made by prevalent theories - that the child will pass through set stages of development towards greater autonomy - do often not hold true. These children form a heterogeneous group - often with distinct and 'spikey' cognitive profiles. The causes of their disabilities may be unknown, or they may be as a result of brain trauma or a specific aetiology or syndrome. They often have associated health and mobility needs, which make it much more difficult to explore and learn from the physical and social environment. This means these children are mainly able to participate in specialised activity settings and need a longer time to process and learn because of sensory and motor constraints, as well as cognitive difficulties. For this group of learners, there are no overriding 'norms' of development and frequently no fixed milestones of physical and psychological development, like sitting up by the age of seven months, or putting two words together by the age of two.

Because of the individualised nature of the development of children with complex additional support needs, and in the absence of set stages of development, there continues to be no common conceptual understanding of their development in educational settings, despite relevant research being conducted in this field. Instead, their development continues to be described in relation to the assumed linear trajectory, and the extent to which they have not yet reached the expected

milestones of typically developing infants. Simmons and Watson (2015), provide a summary of the ways in which their progress is described in the academic literature:

'pre-volitional (they lack free will or agency and cannot move with intent; Farrell, 2004); pre-contingency aware (they do not show awareness of cause-effect relationships; Ware, 2003); pre-intersubjective (they do not represent other people as subjects "like me", and cannot differentiate between subject and object); pre-symbolic or pre-intentional (they do not intentionally communicate meaning to others; Coupe O'Kane & Goldbart, 1998) (Simmons and Watson, 2015, p52).

Early theorists (e.g. Werner & Strauss, 1939) carried out some research on children with disabilities. More influentially, Zigler's (1967) work and his '2-Structure Model' served as a stimulus for the adoption of a developmental perspective to a much wider spectrum of children. He proposed that children with learning disabilities without organic damage proceed in order through the same universal stages of development as typically developing children but at a slower rate and with a lower ceiling. This research matched children according to mental age in order to show that they performed similarly on cognitive tasks (Weisz & Yeates, 1982; Hodapp & Zigler, 1997). Conversely, he demonstrated that children with different organic aetiologies often display a distinct cognitive profile with marked intellectual strengths and weaknesses. The direction of a child's development, as well as the speed, may therefore be fundamentally different from those of a non-disabled child and result in distinct and often non-linear trajectories of development. This means that a child with complex additional support needs may reach milestones in development by different, often complicated, pathways or may simply never reach them.

A small number of studies show that children with complex additional support needs may pass through very similar stages of very early cognitive development such as object permanence and may demonstrate contingency awareness. In a review of the literature on object permanence with an emphasis on research on children with severe disabilities (Bruce & Mohammed, 2009), the findings indicated that children with intellectual disability, physical disabilities, blindness, and autism develop object permanence in a similar sequence although at a slower rate than children without disabilities. Similarly, in a small study which explored the contingency responding of seven infants and children with severe, profound and multiple learning difficulties (O'Brien, Glenn & Cunningham, 1994), the children's responses results suggested that from a mental age level of two months, they were equipped to detect cause and effect relationships and build up a picture of their world based on expectancies about such relationships. It was shown that violations of these expectancies could lead to negative effects such as crying.

In more recent years, technological advances within the area of neuroscience and advanced brain imaging have enabled researchers to explore neural bases which influence the development of children with a specific syndrome, which may lead to specific cognitive impairment. As a result, there is a growing number of studies which explore the distinct learning profiles of children with the same aetiology, including those with Down's syndrome (Cicchetti & Beeghly, 1990), Fragile X syndrome (Dykens, Hodapp, & Leckman, 1994), and Prader-Willi syndrome (Cacioppo, 2002). According to Burack, Hodapp, Iarocci and Zigler (2012), the key to understanding the wider group is to conduct these smaller 'bottom-up' studies of precise homogenous groups which focus on determining the strengths and weakness of a specific aetiology. However, there is as yet little application of the findings of such research to educational practice (Oliver, Woodcock and Adams, 2010) with the exception of research into autism which is a term now embedded in both medical and educational settings.

2.3 Models of Disability and Ecological Theories of Development

The absence of developmental norms for this group of learners informs different practices in education and medical settings. (E.g. using a label or medical categorisation; or referring purely to educational needs). McDermott and Varenne (1995) explain that it is our culture and the focus of our culture which shapes definitions about what is defined as normal and abnormal. Interpretations thus change over time and differ depending upon the political and pedagogical context. Thus, conceptualisations of development are more influenced by societal norms, and attitudes towards disability than they are by the nature of a condition and by research. In this respect, all disabilities are not considered to be the same; some are contested, some are not; some are stigmatised, some or not. This means that disability is also socially constructed at an experiential level - based on how a child's development is depicted and perceived - and how parents come to understand and live with this.

The two ostensibly opposing models of disability - the medical model and the social model - continue to be the most influential and dominant perspectives. The medical model assumes that disability is invariant to time and place and understands a child's difficulties as being based on underlying impairment. Individualised medical interventions are viewed as being the logical responses to this (Conrad & Barker, 2010). Conversely, the social approach to disability proposes that the relation between reduced function and the experience of disability is contingent on environmental, social and cultural factors (Norwich 2002).Thus, the social model is based on the tenets of social constructionism and is influenced by both Goffman (2009) and by the writings of Foucault (2019), which highlight that a condition which is stigmatised is reflective of the social

response and also of power differentials within a society at a given time. Thus, rather than a personal tragedy, parents' experiences of disability are much more politicised and are exacerbated by societal pressure that their child should conform to medically determined notions of normality. The social model thus focuses on the obstacles within society that may limit opportunities for a child or adult with disabilities and the extent to which these can be removed. However, the social model is criticised for its failure to acknowledge the very real impact of the impairment itself on an individual and the extent to which it affects a person, and their sense of self beyond any societal restraints and barriers (Shakespeare, 2006).

The social model and its emphasis on wider societal factors is consistent with ecological models of development which emphasise the importance of environmental influences on child development. Ecological theories, which have been a focus since the 1960s, highlight the extent to which all human development occurs within a multilevel ecological context (Bronfenbrenner, 1994; Lerner & Castellino, 2002). Three such theories are explored below.

2.3.1 Bronfenbrenner's Ecological Theory of Human Development

Most influentially, Bronfenbrenner's ecological systems theory of child development (Bronfenbrenner, 1994) describes the development of children as influenced by different interacting systems. Activities and interaction patterns between the child's immediate surroundings (the Microsystems) make up the Mesosystem. These are influenced by different social settings (Exosystems) that do not contain the child (e.g. the parents' workplace.) The fourth level of ecological systems theory, the Macrosytem, encompasses the cultural environment in which the child lives, including cultural traditions and norms. The different systems interact and influence each other in different ways as the child grows up. In his more recent bioecological theory (Bronfenbrenner & Morris, Bronfenbrenner & Evans, 2000), Bronfenbrenner emphasised the importance of biological and genetic aspects of the person. He placed more emphasis on the proximal processes of human development in his Process–Person–Context–Time model (PPCT), to which he added the Chronosystem, highlighting the extent to which the person and environments change over time. This bioecological theory is more consistent with biopsychosocial assumptions (Engel, 1992) than the earlier ecological systems theory. Yet although this broadens the initial theory to demonstrate the influence of the person and time on development, this later aspect of Bronfenbrenner's theory has been less frequently applied to research.

2.3.2 The Transactional Model of Development

Another important ecological model of development which draws attention to sociocultural influences on child development, and which simultaneously places emphasis on the role of the child is the transactional model of development (Sameroff & Fiese, 2000). This model is particularly relevant when discussing the development of children with complex additional support needs since it highlights the importance of individual differences in terms of what a child elicits from the environment and how the environment in turn shapes his or her progress. According to the authors, the development of a child is viewed as changes which occur as a result of continuous dynamic interactions (transactions) between the child and parent. However, examining developmental outcomes requires attention not only to the parent-child dyad but to multiple sources of external influence, referred to by Sameroff and Fiese (2000) as 'the environtype.' Each environtype is made up of 'codes' (that of the parent, or family, or culture). These codes 'regulate' a child's cognitive and social emotional development so that the child is ultimately able to fit a role defined by a specific context. Sameroff and Fiese define the cultural code as the *'complex characteristics that organise a society's childrearing system and incorporate elements of socialisation and education'* (Sameroff & Fiese, 2000, p145). Thus, the experience of the developing child is partially determined by the beliefs and values of the parents, partially by the family's interaction and history, and partially by the socialisation beliefs, controls and organised practices of the culture. These codes then have a regulatory influence on the parent's behaviour towards the child.

The transactional model of development provides further opportunity to explore how the child's wider environment or 'environtype' is organised in order to develop a child's competencies and how different environtypes (e.g. home/school) interact with the child and with one another. Yet, there are still few efforts to combine analyses of parent-child transactions with transactions in the broader social context such as school (Sameroff, 2009). Kuczynski and Parkin (2009), also highlight that there has been far less focus on the 'descriptive and discovery' stage of research, and more on the testing of the theory (e.g. experimental designs which manipulate the parent or child's behaviour and then use analysis of variance to test interaction effects on outcomes). The authors suggest that qualitative methods would be more appropriate for this purpose and that open-ended interviews with parents may permit further analysis of parental reports of naturally occurring representations of their interactions with their child.

2.3.3 The Cultural-Historical Model of Disability

More recently, Bøttcher and Dammeyer (2016) propose an interactional 'cultural-historical' approach to disability based on Hedegaard's cultural historical theory (Hedegaard, 2009) and influenced by Bronfenbrenner (1994); whilst Bronfenbrenner's ecological theory describes a

person's development as being inscribed into a set of systems, Bøttcher and Dammeyer (2016) emphasise societal norms and discourses about child development; the practices of societal institutions, and the activity of the person within these.

The cultural historical model is also informed by Vygotsky. According to this perspective, primary biological deficits such as neurological or sensory impairments are recognised and viewed in terms of how they influence higher cognitive functions, which in turn affect the child's ability to participate in social activities and to learn relevant cultural tools and practices (Vygotsky, 1993). From this, Vygotsky coined the term 'developmental incongruence' to describe the mismatch between the biological and psychological development of the child with disabilities since for this group of learners, cultural tools and social practices have been developed for typically developing children. This means that a child's development may be hindered rather than promoted in cultural contexts (e.g. school) since organised practices (e.g. assessment) are often rooted in cultural notions of what constitutes progress and may prevent a child with a disability from participating meaningfully

Although largely an ecological model, the cultural-historical model avoids 'over socialising' problems and recognises the reality of individual differences and what this means in terms of a child's development and their ability to engage in social practices. It therefore aims to reconcile both the social and medical model of disability and is reflective of a biopsychosocial model of disability (Engel, 1992). Thus, whilst there is a recognition of underlying aetiologies, their manifestation is dependent upon the interaction of the child with their environment. It is a model which can be applied to many areas of additional support needs education and accords with a moderate social constructionist epistemology (or indeed a critical realist approach).

According to Bøttcher and Dammeyer (2016), 'developmental incongruence' can arise at both a wider cultural level (for example, in terms of prevalent models of disability or common curricular practice) and also at a micro level (e.g. teaching and learning approaches and ways in which the school environment is adapted). Bøttcher and Dammeyer (2016) place particular importance on the child's participation in social practices and highlight the importance of structuring the activities and settings in accordance with their motivators, as a means of promoting development. Rather than adhere to cultural norms of 'age and stage' notions of development, the authors refer to transition periods in the child's development, which arise not in accordance with the child's chronological age, but as a result of the interplay between and changes in a child's interests, motives and competencies. This marks a distinct move away from linear notions of development and a set sequence of developmental milestones which occur at a particular point in the child's development.

2.4 Special Education in Scotland: Categorisations, Legislation and Inclusion -

2.4.1 Categorisations and Legislation

How to classify children as needing different or additional support in school has often been subject of debate, particularly since specific categories and labels are frequently used to try to inform the type of support needed in the classroom (Florian and McLaughlin, 2008). There are concerns that children who are entitled to receive special education services will not receive it due to classification errors. Other children may be falsely identified (Florian, 2008). These definitions are also reflective of dominant societal discourses, norms of development and models of disability and reveal underlying relationships between knowledge and power. For example, many categories which may have originated as medical terms often assume derogatory connotations when they are used negatively to reinforce power differentials and 'difference.' Thus, existing definitions and categories often illustrate more about the current educational system and social context in which they are used than they do about an individual child. A comparison of current categories of disability and educational needs with those used historically helps to shed light on both previous and prevalent pedagogical approaches to supporting the progress of this group of learners.

According to Kirp, (1982), how something is described also says a lot about how it will be resolved (1982). In the UK, there continues to be a contrast between those children whose needs are categorised according to the medical term or disorder and those who are categorised in terms of their educational needs. Previously, categorization was formulated purely in terms of the medical model. The Education (Scotland) Act (1945) operated on the basis of assigning children to a number of fixed medical categories and placed duty on authorities to meet their needs. When Local Educational Authorities set up psychological services, there was an increasing switch from medical diagnoses to those defined in terms of cognitive and other psychological functioning. Professionals and educational psychologists were given the right to determine categories which then informed how needs were met in an educational context. This was reinforced by the 1970 Education Act (England) and the 1974 Education Act (Scotland) which gave those previously deemed to be uneducable access to educational provision.

The Warnock report in 1978 (DES, 1978) had a significant impact on how children with disabilities were viewed; rather than focusing on deficit or on impairment, the report promoted a focus on a child's educational needs. Whilst Warnock recognised that categorisations could be useful to inform planning, it was concluded that the negative connotations of medical labels outweighed the usefulness of these terms. Indeed, an important criticism of the use of medical terms in education is that if impairment is understood as having a purely biological basis, the main responsibility of

any failure to learn is placed upon the child, (Reid & Weatherly Valle, 2004). The overuse of labels has also been described as reinforcing an unequal power differential between a parent and professionals (McClimens, 2005).

The Warnock report coined the descriptive term 'special educational needs.' These were viewed as existing on a continuum and varying in degrees. This term replaced categories of handicap in The Scotland Act (1980) and became embedded in educational practice. The Education (Additional Support for Learning) (Scotland) Act in 2004 broadened this unitary category and devised the new term: 'additional support needs' to include needs that were defined in terms of individual circumstance and the environment. With the implementation of this act, approaches to assessment became much less formal and based on the discretion of the Local Authority and school, placing more responsibility of teachers, often in the absence of specialist qualification. This suggested, too, a reduced assessment role for educational psychologists.

The Doran review (Doran, 2012) ('The Right Help at the Right Time'), set up to review specialist education provision in Scotland, refers to children and young people with 'complex additional support needs.' This term attempts to define the differing needs of this group of learners, viewing them as being at one end of a continuum of what is considered to be additional support needs. The term is broader than those used currently in the English education system (e.g. severe learning difficulties; PMLD (profound and multiple learning difficulties)) and it focuses on educational needs, rather than impairment. The term is reinforced and its definition expanded in the recent 'Milestones' publication: *A child or young person who has additional support needs arising from one or more complex factors or multiple factors (needs that are likely to continue for more than a year) is deemed to have 'complex needs.'* (Education Scotland, 2019, p3). Since the document accepts that a universally accepted definition is difficult to formulate, it is referred to as a 'working description'. Yet, whilst there is as recognition of additional learning needs, there still lacks detail about what this entails in terms of specific resources, strategies, apparatus pedagogy and adult support. Thus, whilst the move way from labels to a focus on needs has had the aim of minimising a deficit-based approach, it can also be viewed as being reductionist and as failing to recognise distinct aetiologies or disorders which may predict a specific profile of learning needs.

For those children with more significant needs viewed at one end of the continuum of additional support needs and whose disabilities are known about at birth or in early childhood, it perhaps makes sense to continue to refer to categories which are used and recognised outside of the school context. Indeed, sixty percent of this population may have a recognised syndrome or disorder that has already been classified medically. When such labels are used at an organisational level (e.g.,

within the school context and in educational policy, as well as in a medical setting) they become a much more powerful way of enhancing practice in the classroom since teachers receive further information and training or indeed have recourse to specifically developed teaching approaches. This is the case for 'autism', a diagnosis which is widely used in both medical and educational settings. Yet, many of the small population of learners who are deemed to have complex additional support needs may have a disorder about which less is known educationally, despite the increase in research in such syndromes. Because of the rarity of such disorders, this research has yet to be applied to educational practice on a wholescale basis, although attempts have been made by a small number of researchers (Oliver, Woodcock & Adams, 2010). This suggests that the current classification system has not been able to bridge the gap between the label (disorder), the school environment and teaching approaches to adequately represent the many facets of what constitutes progress for an individual child.

An attempt to bridge this gap has been that of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) for children and youth (ICF-CY) by the World Health Organisation (WHO, 2007). This was created as a result of an international working group which aimed to develop an integrated conceptualisation of disability across body functions, body structures, activities and participation in different environments using a common language which could be used in different settings. Although medical classifications are accepted as a broad starting point within the ICF-CY, more emphasis is placed on the relationship of the child's abilities to the features of the environment (e.g. the demand on functional skills, physical features, attitudes, etc).The ICF-CY thus aims to classify a child's functional characteristics in different environmental contexts which can then be used to inform relevant intervention approaches. This accords with the cultural historical model (Bøttcher, & Dammeyer, 2016) and is reflective of a bio-psych-social approach to categorisation (Hollenweger, 2014). It also promotes a holistic and non-stigmatising approach to disability and aims to provide a common language which can be used across different cultural contexts and agencies to describe the performance and functioning of children and young people with disabilities.

Although the ICF-CY is beginning to be used more widely across Europe, it is still employed far more frequently as a research tool and is only used in a small number of European educational settings. Initial evaluative research suggests that it would benefit from further adjustments for it to be used effectively in a Scottish educational context. In a Portuguese study which focused on the difficulties in Individual Education Plans (IEPs) for preschool children with ASD using the ICF-CY framework (Castro, Pinto & Simeonsson, 2014), the results highlighted evident omissions. Most

IEPs were about activity and participation, with very few domains covered in both assessment and intervention sections of the IEPs and with little consideration of environmental factors when planning interventions. In addition, the broad coverage of the ICF-CY activity and participation component means that each specific area does not necessarily cover the detail required in an educational context. (Norwich, 2016). One other criticism is that the ICF framework fails to make the distinction between participation occurring at both an individual and societal level. The 'participation' component is also very broad and focuses more on a child's opportunity to participate, rather than the meaningfulness of their participation (Maxwell, Granlund and Augustine, 2018).

This is reflective of the initial focus of the Curriculum for Excellence on providing 'Experiences' and the tendency to adhere to the social model of disability, thus promoting an ideological notion of participation, rather than a meaningful one. Conversely, Moretti, Alves and Maxwell (2012) criticise the ICF-CY framework when used in educational settings for being overtly medical and for focusing on deviance from what is considered to be functional normality. This can then be seen to contribute to existing power relations. However, the ICF-CY is a significant step in the right direction in terms of offering a multidimensional approach which details patterns of functioning and the impact of context, rather than relying solely on medical categorisations. The next step may be to ensure that the tenets of the model and knowledge of a child's label, functioning and participation in different contexts can be applied effectively in a Scottish school setting.

2.4.2 Inclusion and the Curriculum for Pupil with Complex Additional Support Needs

With the publication of the Warnock report (DES, 1978), the increased usage of terms that highlight a child's needs within an educational setting led to a focus on inclusion and how children can be better accommodated within a mainstream educational environment. Inclusion is typically described as the process of increasing participation and decreasing exclusion from the culture, community and curriculum of mainstream school (Booth, Ainscow, Black-Hawkins, Vaughan, & Shaw, 2000). A major driver for inclusion has also been the argument that children's rights are compromised by special education since they are separated from typically developing peers and from mainstream practices. This can lead to a principled, rather than evidence -based focus on inclusive practice (Bøttcher & Dammeyer, 2016).

In the Beattie Report (SEED, 1999), inclusiveness in Scotland was defined as '*abilities and aspirations recognised, understood and met within a supportive environment'* (SEED, 1999, p3). These principles were embedded in the Scotland's Schools Act, (SEED, 2000) which placed a duty on education authorities to develop the personality, talents and mental and physical disabilities of the child or

young person to their full potential. The act also included the 'presumption to mainstreaming' for pupils with additional support needs. However, by defining inclusion in terms of accommodating or responding to the diversity of learners, schools are committed to arrangements required for a small population of pupils. This necessitates recognition that an inclusive school provides supports (e.g. environmental adaptations; equipment; teaching approaches; staffing) which are not necessarily required by the majority. Effective inclusion will thus depend partly on support systems which are specialised for this minority.

Currently, therefore, inclusive approaches in Scotland are reflective of what Low defines as 'soft inclusion' (Low, 1997). This is the position that educational needs should be supported in mainstream settings with additional support being provided where appropriate. At the same time, however, there is a recognition that there is a need for robust support systems, and in some circumstances, for educational provision in different settings (Norwich, 2002). This is especially the case for children with complex additional support needs. The definition of inclusion must therefore be viewed as being distinct from the 'presumption to mainstream' policy since significant pedagogical differentiation and different environments are often needed to support a child's inclusion and sense of belonging (Gillies and Carrington, 2004). Indeed, a review of the relevant literature does not reveal a firm evidence base for inclusive mainstream education as a means of ensuring better outcomes for pupils with disabilities (Lindsay, 2007). In addition, in a study which aimed to establish what works in terms of inclusion (Florian and Black-Hawkins, 2011) the authors found that it was difficult to carry out inclusive practices because of a lack of organisational support. In another meta-analysis of the factors which influence teacher views of inclusion, teachers were very dependent upon extra resources and support if they were to be expected to include children with more significant additional support needs in the classroom (Avramidis and Norwich, 2002). Ironically, this suggests that the foundations upon which effective inclusion depends are frequently missing.

According to Bøttcher and Dammeyer (2016), mainstream settings are arranged to support children functioning within an average range and to accommodate the needs of the typically developing population. This intimates that the prevailing cultural practice of adopting a largely mainstream curriculum (the Curriculum for Excellence) and adhering to inclusive practices may inadvertently place teachers in a vacuum of knowledge about how to support and promote the progress of pupils with complex additional support needs. By adopting practices akin to those employed with the typically developing population, teachers may not be organising learning activities in accordance with the main motivators of a child with disabilities. This may be

exacerbated by the lack of training in the development of this group of learners. As early as 1984, the ACSET report (ACSET, 1984) highlighted the need to focus on the initial and specialist training of teachers of pupils with disabilities. Over thirty years later, however, there are still only a very small number of English postgraduate courses in severe and profound learning disabilities, and none in Scotland, with no move towards reinstating specialist training at an under-graduate level.

Providing a differentiated curriculum for this group of learners has arguably been made difficult due to the continuing tensions between applying common pedagogy and adhering to common conceptions of stage and age-related progress versus adopting teaching and learning approaches that are based on individual need (Lawson, Waite & Robertson, 2005). Yet relatively little is known about how teachers address such tensions in terms of their practice. In a study involving mainstream teachers' attitudes towards teaching children with learning difficulties (Woolfson & Brady, 2009), teachers who felt competent in teaching children with learning support needs viewed factors external to the child, such as the curriculum or their teaching, as contributing to the child's poor learning. This suggests that teachers with more experiences of supporting pupils with this level of needs are more likely to disregard the curriculum if they feel it is not promoting the child's progress. Does it also follow that teachers who lack self-efficacy are more likely to apply the curriculum as prescribed?

There have been moves to adapt the curriculum by those who have a wide range of experience of working with pupils in this sector (Lacey, 2011; Hobbs, 2009) suggesting that teacher experience informs practice based more on individual need. Imray and Hinchcliffe (2014), in their exploration of an appropriate curriculum for pupils with complex additional support needs, propose a broad curriculum only where it is meaningful for pupils. In other words, for pupils with more profound learning difficulties, the focus of the curriculum should be on a narrower range of areas that are concrete in form and relevant to their learning needs. The most recent curricula developed by individual schools in England attempt to achieve a balance by adopting a developmental perspective to learning and life skills, whilst including elements from mainstream subjects (Lacey, 2011; The Bridge School, 2013; Hobbs, 2009; Vale of Evesham School, 2014). Emphasis is placed on providing a relevant and personalised curriculum, with a narrower range of key areas which enable pupils to develop skills in independence and communication.

In Scotland, the Doran review (Doran, 2012), supported a curriculum framework for all, but recognised the extensive adaptations required to ensure that the 'Experiences' advocated by the Curriculum for Excellence facilitate the active engagement of pupils and lead to relevant outcomes.

The report concluded that children and young people require a complex set of arrangements and input from a numbers of specialist practitioners to allow them to progress. This is further endorsed by the Milestones document and accompanying guidance which refers more specifically to learners with complex learning needs who are working at the pre-early level and which attempts to clarify assessment and target setting procedures based on an understanding of individual needs (Education Scotland, 2019). However, it defines milestones as 'important points' in learners' progress, differing from what Bøttcher and Dammeyer refer to as 'transition periods' in the development of this group of learners, and therefore inadvertently endorsing a linear trajectory of progress. The document also fails to make reference to cognitive profiles associated with specific aetiologies.

The implementation of the ASL act (2004; 2009) has granted more legal rights to parents, reinforced by current policy frameworks of consumerism and marketisation. In addition, the growth of parents and voluntary organisations to support children's additional support needs in addition to the framework of legality, offers parents more choice. However,, this is set alongside the policy of inclusion and within the current context of local authority cuts. Ironically, the vagueness of the descriptor 'additional support needs' means that parents (and teachers) lack clarity about what supports and strategies should be in place to support a child's progress. This has meant that parents sometimes seek out a diagnosis, thus promoting medical classification, as a means of securing a placement in specialist provision, since they are less confident about a mainstream setting providing the level of support required. Furthermore, there is a lack of clear evidence regarding the quality of diverse special and inclusive settings (Florian and Black-Hawkins, 2011) or about how children with additional support needs experience different options, especially in the early years.

Perhaps because parents are currently viewed as 'consumers' in an education market place (Riddell, 2008), parents who are seeking a placement for their nursery child with additional support needs have been shown to opt for a mixture of special and inclusive education and see this as the 'best of both worlds' - the 'specialist' input and the 'inclusive' social interaction and community belonging. Inclusive education settings (which are responsive to diversity) are meant to offer these dual benefits. However, in a study conducted with parents who had chosen a split nursery placement for their child with additional support needs (Flewitt and Nind, 2007), the findings suggest that that many parents remained unconvinced that one setting can meet all of their child's needs.

Another frequent conclusion in the literature is that early childhood education and early childhood special education have much in common (Odom & Diamond, 1998) and that 'early years experts do not have to be experts in special education in order to meet [special] needs; they are, already, specialists in how young children learn and develop.' (Mortimer, 1995, p. 165). Yet this viewpoint does not correspond with the literature on the development of children with complex additional support needs which demonstrates that their development does not follow the same linear trajectory and that appropriate strategies may depend on a child's aetiology and individual profile of strengths and weaknesses. This suggests that there continues to be assumptions that a child with complex additional support needs will develop in the same way as that of a much younger child. reinforcing the idea that all children with this level of needs can access learning activities in settings which cater for typically developing children, albeit at a younger chronological age.

2.5 Parental Conceptualisations of Development and Responses

This section of the literature review considers a wide range of studies with diverse aims and methodologies, which endeavours to establish how parents understand and respond to a child with complex additional support needs. Initially, there will be an exploration of a small number of qualitative studies which aim to elicit parental beliefs, expectations and attributions about their child's development and the extent to which these are influenced by the competency level they assume for their child and by prevalent societal norms. Although the analysis includes reference to a large study which aims to compare parental self-report questionnaires with actual parental behaviours towards a child (Sigel, 1992), it was not possible to find research which focused specifically on strategies employed by parents to promote their child's progress. Instead, there is analysis of research which analyses and codes specific parent-child behaviours and which explores how the presentation of a child with a disability influences parent-child interaction. Consideration is also given to the literature which aims to operationalise 'parental resolution' of a child's disability (Feniger-Schaal & Oppenheim, 2013) and 'parental insightfulness' (Feniger-Schaal, Oppenheim, Koren-Karie & Yirmiya, 2012) through the use of criterion -referenced measures, and videos and interviews. This includes further reflection on of how this then informs parental behaviours and indirectly influence child outcomes.

The table below details the main subthemes of this section, highlighting methodologies of the studies cited.

Table 1. Focus of the Literature and Methodology

SUBJECT AREA	FOCUS OF THE LITERATURE	METHODOLOGY AND METHODS USED
INFLUENCES OF 'CULTURAL CODES'	Studies which explore the nature of parents' views and experiences regarding parenting a child with a disability (e.g. Landsman, 2005; Goddard et al., 2000: Bett, 2002)	A small number of qualitative studies employing methods such as IPA and narrative design and also questionnaires to elicit parental responses to their child's diagnosis
PARENT-CHILD INTERACTION AND ROLE OF THE CHILD	Research into behavioural profiles of children with complex additional support needs Research informed by Trevarthen's work (1979) into parent-child intersubjectivity(e.g. Landry et al., 1996)	Aspects of child behaviour are studied, including imitation, vocalising, initiation, and affective expression (Marfo et al., 1998). Counting and coding of child and parent behaviours (verbal and non-verbal) using video analysis. Correlational data is used. Content analysis of mothers' reports of behaviours towards child (Roskam & Schelstraete, 2006)
	Relationship between beliefs and responses (Sigel,1992)	Comparison between parental self-report questionnaires and behaviours towards child

PARENTAL INTERVENTIONS AND RESPONSES	Research which demonstrates parents' engagement in interventions which promote their child's progress (Dawson & Burner, 2011)	Evaluation of interventions involving child and parent (e.g. ABA)
PARENT RESOLUTION AND INSIGHTFULNESS	Studies which explore parents' resolution (Marvin & Pianta, 1996). Research which attempts to assess parental insightfulness, based on criteria established by Oppenheim and KorenKarie, 2002.	Use of measures/questionnaires (e.g. Reaction to Diagnosis Interview) to ascertain resolution and correlation between this and insightfulness. Three components of insightfulness are measured by video. This serves as a basis for interviews with parents about perceptions of child's thoughts and feelings Correlational data is used to link insightfulness to increased maternal sensitivity. Qualitative study to ascertain parental view about positive development of child (Lebeer & Rijke, 2002)

2.5.1 The Influence of the Cultural Code

There is only a small amount of literature focusing on children with complex additional support needs in the early years and on parental views of progress and development. However, ~~th~~ere is a substantial body of research which focuses on exploring parents' *experiences* of raising a child with a disability. Consistent with the cultural-historical approach to disability (Bøttcher & Dammeyer, 2016), these studies emphasise the situated nature of individual parents' experiences and understand these as inseparable from the context within which they exist. The use of qualitative methods of analysis aim to elicit the motivational and affective factors which inform parental views and to ascertain the impact of their experience on their views of their child. This highlights parental views about their child's progress and the impact of cultural norms on their understandings.

Goodnow and Collins, in their book which explored parents' ideas about their child's development. (1990) found that parents' beliefs about their child's development are more influenced by 'ready-made schemas' from their own familial experiences and from their culture than they are by expert opinion. Yet what happens when a parent cannot refer to such schemas? What beliefs do parents possess when their child's development differs markedly from the norm and when previously held assumptions about how their child will progress do not hold true? Although the perspectives of

parenting a child with a disability are still informed by prevalent ideas about parenting,–the qualitative research indicates that they are also largely informed by the meanings ascribed to the construct of disability (Lalvani, 2015; Fisher & Goodley, 2007; Landsman, 2005).

The largest study found was that conducted by Landsman (2005) who acted as a participant observer over the course of two years at new-born follow up appointments for children with identified disabilities. In addition to audiotaping and analysing 130 developmental evaluations, the researcher also carried out 60 one-to-one interviews with mothers of children who had either been diagnosed with a disability or who were at high risk for disability and developmental delay. These took place a month after the hospital appointments. The interviews were coded and analysed with the aim of shedding light on participants' experiences of mothering and their interpretations of disability.

The research suggests that the medical model of disability in which a child's disability and reduced function is viewed as a consequence of abnormality, continues to characterise mainstream western views of disability. The power to diagnose and treat children with disabilities is located within the medical professions. This places medics in a position power and control, automatically subverting the position of parents. Even before birth, the use of medical terms is used to define the unborn child. The vast majority of participants had taken steps to avoid having a child with a disability and had done this with the assistance of the medical profession. Landsman commented that their experience of pregnancy had thus involved a degree of choice and control – something which they lost when their child was diagnosed with a disability.

At the point of diagnosis, participating mothers reported doctors labelling their child as being permanently out with the normal range of development (Landsman, 2005). Already, therefore, the language used within the hospital reinforces the notions of normal child development and the fact that the babies of the participating mothers were not following this trajectory. Mothers described finding these evaluations very hard to bear and hoped that they would still 'overcome' their disability. At this stage, it was evident from the mothers' discourse that they were highly invested in the medical model in the sense that they wished their child to defy medical predictions and to follow a normal trajectory of development which underpinned their understanding of progress.

Paradoxically, Landsman points out that in order to support their child towards a more 'normal' trajectory of development, parents have to accept medical intervention, and must first of all accept the diagnosis of a disability. There were many examples of mothers feeling that their child has been misdiagnosed. This can be interpreted as a means of taking some element of control. The author

indicted that this was not a rejection of the medical model per se, but rather of the medic's judgement, and reflected the hope that their child would instead have a 'normal' outcome. Similarly, some parents refused to obtain a diagnosis, not because they were rejecting the medical model, but because they wished to avoid obtaining a label which would place their child on the 'abnormal' side of the dichotomy. Landsman describes the 'not knowing' as leaving room for the hope that a child would overcome his or her disabilities. This can thus be interpreted as an act of maintaining the child's status as 'normal.'

Guralnick (2005) suggests that parents of children with a disability are required to reconsider many of the goals that they had for both their child and the family unit, a source of stress which is triggered by the diagnostic process, and by missed developmental milestones (Atkinson, Scott, Chisholm et al., 1995). Marvin and Pianta (1996) describe receiving the diagnosis of a child's disability as equivalent to the loss of a hoped for typically developed child. Much of the literature postulates theories of 'chronic sorrow' (Kratochvil & Devereux, 1988) and grief stage theories (Ziolko, 1991). Hornby (1994) presents the process visually as a continuum of stages of reaction, beginning with shock and passing through denial, anger, sadness, detachment and reorganisation until a state of adaptation to the disability has been reached. Wavy lines demonstrate the levels of reaction; whilst one reaction may be the most prevalent, other reactions involved in the process will also be present. The adaptation process is considered to be a normal, healthy reaction to the diagnosis of disability and can be viewed as a form of grieving, similar to that which follows any traumatic loss (Worden, 2008; Kübler-Ross, 1969).

According to Bøttcher and Dammeyer (2016), parents' feelings of grief, anger and anxiety should be understood not only as individual emotional reactions but as reactions to the incongruence between the child's development and cultural norms. Cultural codes such as perceptions of good parenting and motherhood and assumptions of what constitutes a good life impact significantly on parents' reactions to their child's disability. Parents thus experience existential and emotional challenges because of society's awareness and non-acceptance of 'difference'. In a qualitative study conducted by Goddard, Lehr and Lapadat (2000), the authors employed a narrative research design to explore a deconstructed view of disability with parents of children with a disability. Although many stories were consistent with feelings of chronic grief and sadness, parents described the prevailing cultural discourse as exacerbating these feelings. They reported that both the lack of acceptance of their child's differences and also the lack of environmental adaptations served to compound their feelings of guilt and sadness.

Without being able to refer to a common cultural understanding of development and to 'ready-made schemas', parents are reliant on information from medics and other professionals both to understand specific developmental characteristics and to address their child's health needs. In a small qualitative study involving twenty seven parents in interviews about their understanding and experience of parenting a very young child with a severe disability (Graungaard & Skov, 2007), participants requested equality in co- operation with doctors, and referred to the dominance of medics and other professionals for whom they were reliant on to understand their child and their child's development. This highlights the power differential and parents' dependence on others who possess more understanding of their child than they do initially. Parents must also adopt practices that differ from those which are prevalent in the cultural setting. For example, parents of very premature infants must learn about sophisticated medical procedures in the neonatal baby unit and the possible impact of these on their baby's development (Als et al., 2003; Meyer et al., 1995). The way forward usually involves medical intervention, emphasising disorder and limited function and the extent to which the child's development differs from what is understood as the typical trajectory. Parents' reactions will not be uniform but will vary with regard to the complexity of the situation and the cultural-historical practices in which they participate, in addition to their support systems (Dammeyer, 2010).

Although there is only a small literature which explores experiences of parenting a child with a disability, the use of qualitative methodology highlights the emotional toll on parents, particularly in terms of making sense of their child's progress in relation to cultural norms of development and of their view of themselves as mothers. Indeed, societal attitudes towards disability are described as influencing both their view of their child and of themselves, incurring deep feelings of loss and guilt. In Landsman's study (2005), the western and individualistic notions of personhood and agency negate the existence of both the baby and the mother. To be considered a person, is equated with being considered an active agent in the world. There is thus a culturally embedded notion of a 'real child', dependent upon the parenting of a 'real mother.' Interestingly, one of the mothers in the study refers to her brief period as a 'real mother' prior to her daughter receiving a diagnosis of Down's syndrome. Significantly, if a child is not given the status of personhood, and the mother's role is consequently diminished, how then can a mother formulate what constitutes 'meaningful development' for the child?

Parents' stories about guilt cannot therefore be assumed to be the 'normal' response to having a child with a disability, but highlight, instead, parents feeling as though they are 'the problem.' This suggests the need to re-evaluate dominant cultural codes which can serve to disempower and

pathologise parents. It also indicates that any attempt to discern parental views of the development of their child is undoubtedly inextricably linked with pervasive cultural norms of how a child should develop and how they should support this. Given the prevalence of these norms, the qualitative research suggests that parents of very young children with disabilities may not yet be able to construct their child's development other than in relation to these norms. In the longer term, it also suggests, why, in the current framework of marketisation and legality (Riddell, 2008), parents may contest a particular school placement or diagnosis. Indeed, this framework, although divisive, offers a means of reducing the power differential between themselves and professionals in a societal context which continues to diminish the personhood of both a disabled child and their parent.

2.5.2.Parent–Child Interaction and the Role of the Child

It can be assumed that the aspects of development to which parents attribute importance are dependent on the individual needs of the child yet there is little research which sheds light on this The development of communication skills, however, bound up with western ideals of agency and personhood, is viewed to be important by parents across all disabilities (Spiker, Boyce & Boyce, 2002) and is also related to long term outcomes for the child (Chapman, Kay-Raining Bird, Burack, Hodapp, Iarocci, & Zigler, 2012). Consequently, there is a larger body of research in this area.

Parents' perception of the child as an active communicator emerges as a main theme when exploring parents' beliefs about their child's development and their subsequent responses. When the mother views her child as a communicative partner, (Tulkin & Cohler, 1973), this results in a more facilitative interaction style. Rather than using qualitative methodologies and semi-structured interviews to ascertain how a parent communicates with a child with disability, there is a small but more significant body of research which is based on the concept of 'infant intersubjectivity' (Trevarthen & Aitken, 2001). For typically developing children, Trevarthern uses this term to describe how even very young infants are motivated to communicate with their caregivers through their engagement in synchronised interaction. This involves the ability of the mother-child dyad to synchronise gaze, body movements, and vocal sounds, which in turn organises the infant's cognitive and affective experiences and development. Through synchronous interaction, partners become attuned to one another's states.

Yet impairments can affect this development of primary intersubjectivity and early pre-verbal communication. Children with complex additional support needs have distinct behavioural profiles, and often atypical means of communicating that create significant challenges for parents in terms of interpreting their child's intention, responding appropriately and enabling the child to

explore the environment. Various aspects of their behaviour have been studied, coded and counted, including imitation, vocalising, initiation and affective expression (Marfo, Dedrick & Barbour, 1998). These studies indicate that children with disabilities provide fewer cues, are less responsive and respond in less predictable ways. Infants with disabilities often demonstrate delays in smiling and laughing, or more ambiguous negative emotional expressions (e.g. children with autism; Capps, Kehres, & Sigman, 1998). As they grow older, they show differences or delays in prelinguistic skills of joint attention and social referencing (Harris, Kasari & Sigman, 1996), and have lower levels of engagement in play (Landry & Loveland, 1988). Thus, an 'asynchronistic' pattern of interaction may emerge which has implications not only for the child's attachment relationship but also for their cognitive development (Sameroff & Fiese, 2000).

If a transactional perspective is adopted, it can be predicted that individual differences in the child will result in adaptive responses from the parent. Thus, if a child with disabilities presents with atypical responses, the parent may try alternative strategies to maintain their participation. This means that the behaviour of a parent of a child with a disability may look different from that of parents of typically developing children, but that it may have been adapted in order to meet the child's needs. Informed by Trevarthen's work (Trevarthen & Aitken, 2001), researchers have explored mother-child interactions in which the child has a disability in order to discern the characteristics of the communication which promote and enhance child developmental outcomes (see Table 2 below). When attempting to discern specific behaviours which increase child engagement, researchers have been influenced by Vygotsky's notion of scaffolding. Most of the research has been conducted with mothers and young children (often with Down's syndrome) observed in laboratory settings whilst engaged in interactions involving play, teaching, or feeding. Specific behaviours are counted and coded using videotaped data. Whilst both maternal and child behaviours are coded in some research, in other studies, only the mothers' behaviours are analysed. Studies use correlational data which limits the conclusions that can be drawn.

The table below highlights studies which analyse mothers' interactions with a child with a disability.

Table 2. Research on Parent-Child Interaction

TYPE OF INTERACTION /CHILD OUTCOMES	STUDIES	FINDINGS
DIRECTIVENESS	Landry et al. (1996)	Involved children with Down's syndrome and their mothers. Mothers were more directive when participating in a less
	Roach et al., 1998.	Examined mother-child interactions amongst 28 toddlers with Down's syndrome aged 11-30 months with developmental ages between 10-17 months. Comparison groups of typically developing children were matched on chronological or development age. Mothers of all three groups were found to be responsive to their child's behavioural signals, but mothers of children with Down's syndrome engaged in more directive behaviours than mothers of children in the other two groups. Mothers of children with Down's syndrome used more supportive behaviours such as praise and scaffolding behaviours, e.g. holding out an object.
	Cielinski et al., 1995.	Involved children with Down's syndrome and typically developing children. Maternal directedness was positively and significantly associated with maternal response contingency, but not with maternal intrusiveness

STRUCTURE	Lieberman et al., 1995. Landry et al., 1996.	Mothers of 1-year old infants with delays were more directive and engaged in physical interaction more than mothers of typically developing one-year olds. Preterm infants' exploration of toys was associated with their mother's scaffolding behaviours of providing structured strategies to maintain their infant's attention, but not with redirecting strategies.
CHILD OUTCOMES	Crawley and Spiker, 1983.	A moderately directive but responsive style was associated with higher Bayley developmental scores for a sample of two-year olds with Down's syndrome.
	Cielinkski et al., 1995.	Mothers' use of contingent responses based on their child's focus of attention was positively related to child participating and intentional communication during play for children with and without Down's syndrome.

The studies help to discern the types of behaviours which may promote a child's development. In studies involving typically developing children, high levels of responsiveness and low levels of directives have optimised child development (Bornstein & Tamis-LeMonda, 1997). Indeed, this fits with cultural notions of agency and control that are promoted in children as they develop. Early studies which involved children with disabilities viewed a high level of maternal coerciveness as potentially preventing a child from evolving (e.g. Mahoney & Robenalt, 1986). Interestingly, this is based on the cultural assumption that this level of maternal direction will impede the development of autonomy and agency that is valued in western society. However, more recently, many more studies have recognised the use of such behaviours as being purposeful and as a positive means of promoting the communication of a child with a disability.

In a qualitative study, the behaviours of 31 mothers were analysed on the coercive-induction dimension (Roskam & Schelstraete, 2006). Further content analyses of mothers' reports

demonstrated that their behaviours were adapted to their child's characteristics:- to the child's disability, personality traits and behaviours. Mothers with children with severe disabilities used more coercive behaviours whilst mothers of children with visual or hearing impairment used more inductive approaches. Thus, rather than a mother's coerciveness being indicative of their difficulty in reading their child, mothers instead mediated their use of inductive and coercive behaviours according to the child's understanding and the context. This suggests that mothers understood how their child is developing and how to promote their progress and means of communication. However, the findings were based on self-report and linked to hypothetical situations. In addition, there was no attempt to discern if these behaviours were based on a maternal understanding of a child's strengths and difficulties and means of communication. Further research would be necessary to establish if the behaviours described by the participating mothers were evident during parent-child interaction and if professionals supporting the child would concur with mothers' interpretations of behaviours.

Research has found that it can be difficult to determine the direct relationship between parents' beliefs about their child's development and the responses that they employ to promote this. In a study which involved 240 families, half of whom had a child with a communication disability, (Sigel, 1992), behaviours related more consistently to beliefs when these were detailed by parents in a self-report questionnaire and linked hypothetically to certain situations. The relationship between behaviours and beliefs was not as evident during observed teaching situations. The authors concluded that their broad definition of parental beliefs - world views regarding child development - could not be readily linked with specific parental behaviours. For example, whilst two parents may agree that their child learns through exploratory play, the strategies that they employ to support this may be markedly different. The authors recommended working with parents to obtain more detailed accounts of the behaviours that they report to use which reflect their world view of development. This should take place prior to conducting observations of parent-child interaction.

The study above highlights the difficulty of conducting research which aims to explore parental views about behaviours and strategies, and the application of this to practice. This is rendered more difficult by the impact of the context on the behaviours of both parents and child, and also the difficulty of trying to develop reliable codes to ascribe meanings to behaviours that can be applied across contexts. The age of this research and limited outcomes suggests the need for further reflection upon ways of measuring parent-child interaction and behaviour, particularly when those

conducting the research require an in-depth knowledge of a child and an understanding that a child's responses may diverge significantly from expected norms for children of that age.

2.5.3 Parental Interventions

What the parent believes about the cognitive capabilities of the child is likely to have an influence not only on the practices they employ but also on the interventions in which they engage to promote their child's development. Strong advocates of the social model have criticised parental commitment to rehabilitative therapies advised by medics since this promotes an individualised within-child model of disability and results in less focus being placed on addressing the disabling conditions of society. Although mothers at the point of diagnosis believed that prejudices in society remained the biggest barrier to their child, rather than the disability itself (Landsman, 2005), their narratives in Landsman's qualitative study highlighted the fact they had more faith that their child could be changed, rather than society. They embraced the social model in the sense that they believed social barriers served to create and exacerbate the disability, yet at the same time they adhered to the medical model by continuing to seek within-child interventions which would mitigate the impact of the disability. Indeed, Landsman (2005) describes mothers' desires to fix their child being based on the belief that they cannot be a good mother unless they maintain their child's linear progress. This emphasises the idea of diminished motherhood reinforced by cultural norms of parenting.

From the 1980s, several programmes for intensive treatment of general or specific impairments have become available. Often, the intensive treatment and training programmes are based on medical categorisation and diagnosis with the aim of minimising the disability. For example, the Applied Behaviour Analysis (ABA) programme (Keenan, Kerr, & Dillenburger, 2000), is an early and intensive behavioural intervention for children with autism. The aim of the programme is to improve language and adaptive skills and decrease maladaptive behaviours. At a cultural level, the development of such programmes adheres to the medical model of disability, in the sense that the aim of the training is to move towards a more culturally accepted form of development. It is perhaps the case that parents who are still embedded within the medical model may be more eager to engage in programmes which promote typical development.

There have been some studies which demonstrate the positive effect of the ABA programme (Dawson & Burner, 2011) but the effects are not strong and further controlled, longitudinal studies are required in order to determine its long-term impact. Interestingly, despite small changes in their child's function, parents often report being satisfied with such programmes. Part of this has been attributed to the active involvement of the parents in their child's development (Von Tetzchner,

Verdel, Barstad, Gravås, Jahnsen, et al., 2013). Indeed, by spending so much time with their child, such programmes may inadvertently promote a better understanding of their child's strengths and weaknesses. Is it possible to hypothesise that the parents' increased interaction with their child may then result in them being less likely to aspire to developmental norms, despite this being the aim of such programmes?

2.5.4 Parental Resolution and Insightfulness

Parents' engagement with rehabilitative interventions may ultimately be moderated by their wish for a normal life in which they can play with their children, rather than measuring their achievements by a fixed scale. There have been few studies which explore the extent to which parental conceptualisations of development differ according to the age of the child with disability or the time since they received a diagnosis. An analysis of the existing literature suggests that at the outset, parents adhere to the linear trajectory of development but that they may reach an eventual acceptance and embracing of their child (Landsman, 2005; Goddard, Lehr & Lapadat, 2000). This suggests that in the early years, parents are more likely to pursue cultural norms of development for their child. The parents' stories reflect a changing perspective of their child's disability over time as they come to understand the child as him or herself. For some, this involved accepting the non-normative qualities integral to their child, resulting in a reconceptualisation of what they considered 'normal' (Landsman, 2005). It may be that this new normal led to a different conceptualisation of development of the child, and to a focus on different aspects of their child's progress, although this was not explored in the study.

The change in both attitudes and responses to their child is reflective of the fact that parents have incorporated the child's diagnosis and the impact of this on the child's development into their representation of the child. In the literature, this has been termed 'parental resolution.' (Marvin and Pianta, 1996) and has been measured using a Response to Diagnosis Interview. There has been some research which has found a positive correlation between maternal resolution about their child's disability and maternal sensitivity (Feniger-Schaal & Oppenheim 2013). Marvin and Pianta (1996) interviewed parents of children with cerebral palsy using the Reaction to Diagnosis interview (RDI) and asked them to reflect upon the changes in their feelings and responses towards their child's difficulties. Mothers classified as 'resolved' (i.e. having accepted the child's disability) on the RDI were more likely to be sensitive to their child's signals and to match their behaviour according to the child's strengths and weaknesses (Marvin & Pianta, 1996). Parental resolution is marked by an integration of the facts and realities associated with their child's diagnosis, along with

their emotional reactions. The authors also found an association between the parent's resolution and the children's secure attachment

In the qualitative study conducted by Landsman, (2005), the mothers were reported to have reached a deeper understanding of their child in the security of their home, and away from the cultural and medical concepts of disability or pressures of mothering. Yet this suggests that this individualised understanding of their child was context specific – and required a deliberate dismissal of cultural norms. Indeed, in a study which explored parental acceptance of 61 mothers and 60 fathers of children with autism or epilepsy, only half of the mothers were found to be 'resolved' (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010). Rather than this being contributable to their difficulty accepting their child's needs, this was attributed to the negative perception of raising a child with a disability. This highlights again the error which professionals may make by adopting individual grief models when attempting to understand parental responses to their child's disability, rather than taking into consideration the impact of prevailing cultural codes on parental resolution. It also suggests that any measure designed to assess parental resolution must take into account both contextual factors and also wider prevailing norms. These factors are not considered in the Resolution to Diagnosis interview.

The outcomes of the Landsman study (Landsman, 2005) indicate that the concept of resolution evolves and is dependent upon a range of factors. It is probable, too, that a parent's ability to respond to the cues of their young child with a disability may be dependent upon context and whether they feel a sense of 'diminished motherhood' or whether cultural pressures encourage them to respond in what they believe is an acceptable way of interacting with their child, rather than based on the potentially atypical responses of a disabled child.

A greater level of parental sensitivity is one component of what Oppenheim and Koren-Karie (2002) define as parental 'insightfulness'.

They describe insightfulness as including the following:

1. The capacity to see things from the child's point of view; considering the motives underlying a child's behaviour and accepting that the child has his or her own likes and dislikes and needs.
2. Maintaining an emotionally complex view of the child with both positive and negative features.
3. Demonstrating openness when faced with new and sometimes unexpected information about the child and being aware of their own attitudes in this process.

These three components are measured through the use of video which then serves as a basis for interviews (the insightfulness assessment) with parents regarding their perceptions of both their own and their child's thoughts and feelings during the clips. Responses are rated from 1 to 7 on concepts such as 'insight into child's motives.' According to the authors, 'insightful' parents read children's emotional signals accurately and respond to them appropriately, in a way that enhances the child's emotional regulation and sense of security.

Initial studies of insightfulness which explore the interaction of mothers and typically developing children demonstrate increased maternal sensitivity during interactions when mothers had been rated as insightful (Oppenheim & Koren-Karie, 2002). In a study of the insightfulness of mothers of children with learning disabilities, the authors found a positive correlation between maternal insightfulness and security of attachment (Feniger-Schaal, Oppenheim, Koren-Karie, & Yirmiya, 2012). Various features of insightfulness were comparable to those evident in the mothers of typically developing children; parents were able to explain their child's thoughts and feelings and likes and dislikes and could also attribute motivations to their child's behaviours. This was in contrast to parents rated as less insightful who revealed real difficulty understanding a child's motives. Insightful parents also understood that their child could enjoy engaging with a toy or object, even if they were doing this in a way deemed to be atypical. The same parents highlighted both positive and negative aspects of their child's behaviours.

However, since the insightfulness measure is based not only on the mother's contribution but also the child's, use of the measure when applied to a child with complex additional support needs requires the person conducting the assessment to have a deeper understanding of how the individual child in question communicates their needs. There is also no explicit reference to the influence of cultural norms, and how these may influence both parent and rater responses to a child's behaviours. This suggests that there needs to be further research conducted with parents of children with disabilities before applying the research more widely to this sector.

The findings from initial insightfulness studies informed an intervention designed by Barnett, Clements, Kaplin-Estin and Fialka, (2003), the aim of which was to promote adaptation to the child's disability. This focused on helping to accept the child's disability and building an accurate perception of the child's strengths and disabilities, which it was hoped would facilitate more 'synchronous' interactions between the parents and child. It also aimed to facilitate parental adaptation by validating parents' feelings, identifying their strengths and increasing their support. Although the authors detailed the outline of the programme, there is as yet no evaluation of its impact and no wider implementation evident in the literature. This suggests too, that there may be

a dearth of such interventions with this population of parents and again, a failure to include the dominant social discourses around disability when discussing parental views of their child's development

A qualitative longitudinal study conducted by Lebeer and Rijke (2002) details the life histories of 20 children with significant brain impairment as a means of eliciting further information about the ecological factors which influenced their development. This was the only study found which had explicitly explored parents' beliefs and conceptualisations about the development of their disabled child and their experiences of strategies that had promoted their child's progress. All participating children had shown marked functional improvement despite their original diagnosis and were all of school age and above. This study evolved from earlier studies which had demonstrated gains in children with cerebral palsy, all of whom had ceased treatment and some of whom had outperformed children who had received years of treatments (Paine, 1962). These findings were contrary to clinical experiences which attribute development in cognitive motor and social domains to regular intervention and stimulation. For this reason, the authors adopted a qualitative approach and collated relevant medical data and analysed parent/carer interviews in order to explore the connections between children's cognitive-motor-development and the psycho-social interactions and experiences.

One finding was that the children's development did not develop in a linear way but proceeded in a process of 'ups and downs' and frustrations and successes. For example, a number of children appeared to go through periods of 'struggle and release' or periods of passivity before being awakened by someone in the environment challenging them. This indicates that it is important to keep stimulating a child for a long time, even if the child does not demonstrate a response. Although children in the sample had accessed specific interventions such as Bobath (Bobath, 1975) or conductive education programmes (Read, 1992), analyses of the interviews suggested that simple daily activities out with therapeutic interventions were deemed to be just as important in terms of promoting development. Parents' qualitative comments suggested an ability to follow their child's needs and provide appropriate learning opportunities which enabled the child to see the function of a specific skill, and to promote this in a goal directed way. For example, one parent put a cat on her son's lap as a means of promoting his looking and head flexion; another child learned to walk on a sandy beach as means of overcoming his fear of falling; a child's hand-use was promoted by playing with water or sand.

Although the study involved only a small sample, the outcomes suggest that new abilities appear to emerge as a result of this interaction between the child and key people around them. These

people trigger the child's will by offering mediating activities and challenge and support. An important step which corresponds with the studies on insightfulness seemed to be that fact that parents became more attentive to the signs of the child's progress and hidden potential, rather than remaining unhappily focused on a child's deficits. They attributed more importance to small acquisitions and experienced renewed motivation. They then began to explore different ways of stimulating their child. The authors concluded that the child's ecology, in the form of committed adults who provide a mediating and stimulating environment, contributes to promoting the development of a child with disabilities. The fact that the parents in this study provided mediating environments is an indication that they demonstrate 'insightfulness' and are able to provide activities based on an understanding of a child's motivators and of what they will find rewarding. The child's sense of agency is also evident in the parental accounts. However, it is worth noting that the study includes the parents of children who have surpassed expectations. Perhaps it is easier to discern signs of progress and potential if they are more reflective of the cultural norms of development and if they signify a sense of agency, so integral to the western concept of personhood. It was not possible to find research which explored the parental views of children with complex additional support needs whose development continues to remain significantly different form that of typically developing peers. It could be hypothesised that insightfulness may be far less attainable for parents of children with this level of need.

2.5.5 Summary and Proposed Intervention Approaches

Qualitative research on parental views of parenting a child with complex additional support needs suggests that prevalent cultural codes - in particular, the medical model - may hinder rather than promote parental resolution by highlighting the child's deficits in relation to assumed stages of development and by encouraging interventions which aim towards culturally-bound norms. Studies suggest that this is more evident when the child is young, and perhaps before the parent has achieved resolution. This is not surprising, given that the prevalent cultural code can make mothers feel unworthy unless they maintain their child's linear progress (Landsman, 2005).

However, there are a number of studies which suggest that parents often adapt their communication and responses to meet the developmental needs of their child. In addition, initial findings from insightfulness studies (Oppenheim & Koren-Karie, 2002: Fenigaar-Schaal, Oppenheim & Koren-Karie, 2011) may correspond with Lebeer and Rijke's research (2002) in which parents viewed their child's outcomes as open-ended and multiply determined. These studies suggest that further research may be able to demonstrate if parents may be able to better promote their child's development if they adopt a realistic view of their child's strengths and weaknesses and encourage interaction which may be atypical, but which is enjoyable and rewarding

to the child. Hornby (1994), in his explanation of his model of parental adaptation to disability, suggests that the stage of reorganisation, characterised by realism about the situation and hope for the future, may be the stage at which parents wish to engage in interventions to promote their child's development.

Further exploration of conceptualisations of development may enable us to identify parents who can be deemed to be more 'insightful' and may help to establish the impact, if any, on the responses and practices they employ. Do parents of children with complex additional support needs better promote their child's development if they possess accurate representation of their functioning and needs? Is 'parental insightfulness' more evident when a parent has reached a stage of acceptance or 'resolution' about a child's disability – and thus when a child is older? And can parents be expected to achieve resolution when the prevailing cultural code – that a child should follow a linear trajectory of development and demonstrate a sense of agency – may result in them feeling unworthy or at fault as a parent or may make it incredibly difficult to accept their child's progress? A parent's 'realistic' view of their child's progress thus requires them to disregard deeply embedded cultural expectations of progress which are also linked to the status of both the child and parent.

In order to achieve 'development regulation', Sameroff and Fiese (2000) suggest that interventions should be based on an assessment of environmental influences on development and should focus on one or more of the three areas: re-education (teaching others how to respond to the child), redefinition (strategies directed towards more optimal interactions through an alteration in beliefs and behaviours) and remediation (interventions designed to incur changes within the child). Thus, although Simmons and Watson (2015) highlight that research often focuses on how intervention strategies have changed a child's behaviour, Sameroff and Fiese (2000) emphasise the importance of focusing on adult's beliefs and behaviours and how these can ameliorate interactions with a child. It is possible to hypothesise that 'redefinition' interventions (Sameroff & Fiese, 2000) which aid parents in developing a better understanding of their child's strengths, difficulties and motivators may in turn aid parents in achieving some kind of resolution of their child's disability? Studies aimed at promoting parent-child engagement and a child's responsiveness, whilst taking into account cultural norms and influences, may therefore enhance parental responsiveness and insightfulness, which may in turn further the child's development.

2.6 Teachers' Conceptualisations of Development and Responses

The transactional model of development is explored most easily in the relationship between parents and children. However, explaining developmental outcomes requires attention to other multiple sources of influence, as well as to the parent-child dyad. Of particular significance is the influence of the nursery and school environment, where the child begins to spend more time. Indeed, since children with complex additional support needs often have difficulty generalising their learning, close collaboration between home and school may facilitate the application of newly acquired skills to both environments. Here, the cultural-historical model of development enables us to consider not only a child's diagnosis and learning needs, but also the extent to which the practices and teaching activities are based on assessment of their needs or on a curriculum that has been created with the development of typically developing peers in mind. Teachers' beliefs about inclusion and about the progress of children with complex additional support needs may influence decisions about how to teach, and what approaches to adopt yet there is little research about what teachers and other education staff believe constitutes progress for this group of learners (Lalvani, 2015).

This section of the review uses the transactional model of development (prevalent cultural code; presentation of child; teacher responses, teaching approaches and teacher-pupil interactions) as a framework to explore teachers' conceptualisations of development for children with complex additional support needs. The table below details the main subthemes of this section, detailing the methodologies of the studies cited.

Table 3. Teachers' Conceptualisations of Development: Literature and Methodology

Subject Area	Focus of the Literature	Methodology and Methods used
The Influence of the Cultural Code: Teacher Beliefs about Inclusion	Research carried out under the umbrella of 'inclusion' to discern teachers' .views about teaching children with disabilities within mainstream setting (e.g. the SET Project; Jordan et al., 2010)	Mixed methods: Questionnaires/ Qualitative interviews
Teacher Responses and Teaching Approaches	Behaviour state research (e.g. Foreman et al., 2004; Guess et al, 1993.) Levels of Engagement (Carpenter et al, 2015 Creating a responsive environment (Ware, 2012) Examples of aetiology-specific approaches (e.g. TEACCH, Mesibov et al., 2005)	Analysis of coded pupil behaviours and level of alertness in response to activities/environment
Teacher-Pupil Interaction	Impact of Intensive Interaction approaches on pupils' interactions and teacher views. (Hutchinson & Bodicoat, 2015)	Small scale evaluative studies employing an AB/ABA design and coding the behaviours of one or a small number of pupils with complex additional support needs to assess increase in communication
Evaluation of Teaching and Assessment Approaches	Evaluative studies of teaching and assessment approaches	Small-scale evaluative study of pupil progress according to 3 criteria (Hobbs, 2009) Questionnaires to obtain teacher views of assessment approaches

2.6.1 The Influence of the Cultural Code: Teachers' Beliefs and Inclusion

Teachers and other education staff form a very different population from parents. Although they are vested in the progress of their pupils and form part of the multi-agency team supporting the child, they are not as embedded within the medical context as parents, nor are they as emotionally involved with the child. This means that they are not as closely impacted by cultural norms of development, and by the power differentials created by these norms. Whilst parents' adherence to a linear trajectory of development may be tied up with their feelings about their worthiness as a parent or mother, (Landsman, 2005), it can be presumed that this is not the case for teachers. However, this does not necessarily mean that they are less likely to adhere to a typical trajectory of development. Teachers are also influenced by their own 'cultural codes'. At a macro level, this

includes models of disability, prevalent policy, pedagogy and the curriculum. This then informs practices at a micro level, including the organisation of school routines and timetable, and teaching practices. Indeed, without a common conceptual understanding of the development of this group of learners, it may be that teachers adhere to a linear trajectory of development or are more reliant on the mainstream curriculum and current educational policy in terms of gaining an understanding of what constitutes progress for this group of learners.

The transactional model of development highlights the importance of child effects and how these inform beliefs and elicit responses in adults (Sameroff, 2009). Despite this, the influence of child characteristics on teachers' beliefs has not been explored in relation to the population of children with complex additional support needs. Instead, the research focuses on teachers' views of inclusion after having had experience of teaching a child with complex additional support needs within a mainstream classroom. What is lacking is any attempt to encourage teachers or nursery staff to scrutinise the policy of inclusion and to explore the impact of both this and other cultural factors (e.g. models of disability or the curriculum) on their beliefs about children's development. There are also very few studies which explore the influence of affective or motivational factors on their beliefs (e.g. personal experience of disability or their relationship with and experience of the children with whom they have worked.) Nor are there any studies which attempt to establish if beliefs about progress are based on an in-depth understanding of a child's strengths and difficulties.

Teachers report that they lack knowledge about the children they are meant to include (Janus, Kopechanski, Cameron, & Hughes, 2008). This is perhaps unsurprising given the current curriculum model in Scotland, the Curriculum for Excellence, which is underpinned by cultural norms and by a linear trajectory of development. Without recourse to training in the development of this group of learners, it can be hypothesised that much of their knowledge is gleaned 'on the job.' Interestingly, in a study which explored teachers' attitudes towards pupils in their mainstream class with a mild or severe disability, (Cook, 2001), only 16.7% (8 of 48) of teachers indicated that they would be most relieved to have those with severe disabilities removed from their class. Although these findings may appear counterintuitive, the teachers' attitudes support the theoretical perspective of the model of differential expectations; because teachers can readily recognise the disabilities and see the difference, they are more accepting of it.

However, these findings do not shed light on teachers' understanding of this difference and the extent to which their beliefs about a child's development can promote their progress. Significantly, the author suggests that the recognition of these differences may in fact result in teachers feeling that they are unable to address the different characteristics and needs of these pupils. If teachers

feel that they do not know how to appropriately instruct pupils with severe disabilities, or if they presume that their development should follow the same trajectory as those of typically developing peers, then they may hold low expectations for them, and feel that educational progress is beyond their capabilities. They may then be less likely to employ specialist approaches. Indeed, other research highlights the fact that the more significant a child's disability, the less confident teachers feel about being able to teach them within an inclusive setting (Avramidis, Bayliss, & Burden, 2000). In addition, since there is still a notion that 'early years workers are specialists in how young children learn and develop (Mortimer, 1995) they may be less likely to be made aware of how the development for children with complex additional support needs from that of their peers.

In the study conducted by Avramidis and Norwich (2002), teachers who were interviewed about their experiences of including a child with a disability in their class, developed a more positive attitude to inclusion if they viewed the relationship with the child as being dynamic, rather than being intrinsic to the child. This corresponds with both the transactional model of development and cultural-historical model, both of which emphasise the impact of setting and transactions upon a child's development. If the school is aware of the impact of ecological factors (e.g. classroom environment; social setting) upon the child's progress, they are more likely to adopt and develop teaching methods which correspond with the needs of the individual (Avramidis & Norwich, 2002). Conversely, if teaching staff view a child's impairments as being intrinsic to the child and outwith the control of the school (and indeed, them), this impedes the development of teaching approaches and may exacerbate rather than promote the child's progress. This suggests that increased experience of teachers or indeed the overall ethos of the school or nursery, may lead to an increased understanding of how to meet individual learning needs, and thus enable a teacher to put in place strategies and approaches which reduce the incongruence between a child's needs and the school setting.

The findings from the study conducted by Avramidis and Norwich (2002) are reflective of the outcomes of the SET Project (Supporting Effective Teaching Project), a set of studies which explored the relationship between general education teachers' beliefs about disability, their role in inclusive classrooms and how these are related to teaching practices (Jordan, Glenn & McGhie-Richmond, 2010). A narrative interview was developed in which teachers recounted a sequence of events for two pupils with whom they had worked. The authors found that approximately one quarter of the participants held 'pathognomonic' beliefs about disability – i.e. beliefs which focused on the intrinsic impairment of the child and attributed failing in learning solely to the child's difficulties. Conversely, 20 % of the sample of 33 teachers held views reflective of the social model

of disability - thus emphasising the role of the teacher and the environment in reducing barriers to learning. It should be noted that teachers' views could be placed along a continuum, with teachers expressing components of both views. Perhaps those with a more balanced view expressed views more consistent with those of the proposed social-cultural historical model of disability, taking into consideration both the child's disability and the impact of the environment and approaches on children's progress. Would this group of teachers be more likely to engage in practices which better promote a child's progress? This is not evidenced in research.

Further research involving the same participants suggested that the beliefs about disability were closely bound with individual teachers' epistemological beliefs about the nature of knowledge, ability and learning. The BLTQ (Beliefs about Learning and Teaching Questionnaire) (Glenn, 2018) was administered to the 33 teachers (Glenn, 2007). Teachers' personal epistemological beliefs were defined as either 'entity beliefs' - which hold that ability is a fixed and stable trait, versus 'incremental beliefs' - the belief that ability is malleable and amenable to improvement as a result of the correct environment and learning conditions. A significant correlation was found between teachers' beliefs about disability and whether they held entity or incremental beliefs about the nature of learning.

These findings were endorsed in a very small study conducted as part of a Master's thesis which involved teachers who were part of the SET project over a period of 5 years from 1999 to 2004 (White, 2007), the findings revealed that the teachers' beliefs had not changed as a result of experience of teaching children with disabilities but were instead reflective of the beliefs that they had possessed at the time of entering the projects. The participants belonged to a school system which placed significant emphasis on inclusion, thus suggesting that the ethos and prevalent cultural code had not altered their beliefs. These initial findings suggest that teachers need a broader understanding of knowledge and of how children learn – especially those children who follow an atypical development pattern – if they are to assume more ownership for the role they play in promoting the development of children with complex additional support needs. However, the data should be interpreted with caution since the study involved only 5 participants and was carried out within the education system in Canada. This makes it very difficult to generalise the findings.

Other research draws attention to the influence of the headteacher on positive teacher beliefs about teaching a child with additional support needs within a mainstream class. In a review of relevant literature, it was concluded that mainstream teachers have a greater tolerance of integration if headteachers are supportive (Forlin, 1995). This suggests that an ethos which encourages staff to

adapt the environment and strategies to meet individual needs will impact positively on teachers' beliefs about inclusion and their sense of ownership. Furthermore, it may be the case that the teachers' wider epistemological beliefs have been largely influenced by norms of development and by assumed 'ages and stages' which are so deeply engrained in our common understandings of development. What was not established was the link between cultural norms and epistemological beliefs and how they inform either individual or entity beliefs.

The SET studies involved teachers working in a mainstream setting. Is it probable that teachers with a particular set of epistemological beliefs or a more flexible interpretation of development are more likely to choose to work with children with more complex additional support needs? Very little is known about the beliefs of teachers working in an ASN setting. In a doctoral study completed by Jones (2002), all teachers participating in the study had been working in the sector for over 5 years. The author reported that they were strong advocates of a developmental curriculum in the sense that they focused on aspects of development that were important in helping the individual pupil. This included a major focus on communication, in addition to cognition, personal and social education and movement. Their comments reflected an understanding of how their pupils learn; they highlighted the slower pace at which pupils learned, and the need to match the activity to the ability level of the pupil. The findings suggest that responses are individualised, according to their knowledge of the pupil and that the teachers held what Jordan, Glenn, & McGhie- Richmond (2010) refer to as 'interventionist' views of disability.

These findings are endorsed by the literature review conducted by Avramidis and Norwich (2002) on teacher beliefs and inclusion in which several studies highlight teachers' experience with children with additional support needs as being an important variable in shaping teacher attitudes towards inclusion. Here, the 'contact hypothesis' suggests that as teachers implement inclusive programmes and therefore get closer to students with significant disabilities, their attitudes might become more positive. The same literature review highlighted the importance of teacher training in building capacity amongst staff and involving positive attitudes towards supporting children with needs.

It can thus be hypothesised that teachers with an in-depth knowledge of an individual child may possess an understanding of the motives underlying a child's behaviours, as well as demonstrating familiarity with the child's strengths and weaknesses and their ways of communicating likes and dislikes. There has as yet been no research which attempts to establish if staff working in this sector demonstrate 'insightfulness', akin to that described in the studies involving parents (Feniger Schaal, Oppenheim, Koren-Karie & Yirmiya, 2012). This highlights a future avenue for research since it

may be possible to measure the three components of insightfulness by videoing teachers in class and then conducting interviews with them. Does it follow that 'insightful' teachers better promote progress based on an understanding of the child's individual learning needs? Given that they are not subject to the same power differentials as parents of children with disabilities, is it probable that insightfulness is easier to achieve? Do teachers' beliefs about the development of this group of learners change as they gain experience or, as White (2007) suggests, do they continue to reflect their existing epistemological beliefs about the nature of learning? In addition, does the adoption of a general curriculum framework hinder teachers in achieving insightfulness and promoting progress since it is based on a linear trajectory of development, rather than reflecting the individualised needs of this group of pupils?

2.6.2 Teachers' Responses and Teaching Approaches

In the SET project (Jordan, Glenn & McGhie-Richmond, 2010), the studies found that teachers' beliefs informed their teaching practices. In the study conducted by Glenn (2007), those teachers who rated highly on the student engagement subscale of the Classroom Observation Schedule also recounted taking more responsibility for the learning of the pupils with disabilities, and tended to attribute barriers to learning to factors within their influence such as adapting teaching techniques and the classroom environment. This is consistent with the work of Ware, (2012), who advocates the establishment of a 'responsive environment' by encouraging teachers to take into account environmental factors (e.g. positioning; ability to cope in a group; sensory factors) when planning for pupils. Glenn (2007) found that teachers with interventionist views about disability were also more likely to report preferring pupil-centred instruction. Although the studies involved only a small sample size and included pupils with less significant impairments, the findings suggest that more interventionist views of disability may result in practices which respond to individual needs. However, further research is needed to discern if there is a direct link between teachers' beliefs about pupils' development and their subsequent responses.

In their review of teaching strategies for pupils with special educational needs, Norwich and Lewis (2001), explored an individual versus a group differences position e.g. whether the distinct needs of a group of learners with the same categorisation or descriptor of educational needs leads to clear implications for teaching approaches, or whether pedagogy should be informed by the needs of an individual pupil with complex additional support needs. The authors conclude that there are very few studies which support the general differences position of pedagogies and suggest that common pedagogic principles are relevant for all pupils.

Yet the literature on the development of pupils with complex additional support needs provides much support for distinct teaching approaches which reflect the complexity of needs of this group of learners; this includes their often non-linear development pattern, their difficulty generalising new skills and the fact that pupils with more profound learning difficulties often plateau in their learning or show regression as a result of illness (Imray & Hinchcliffe, 2014). Indeed, the extent of the cognitive difficulty, in addition to associated mobility and health issues means that children are deprived of exploring many aspects of the physical world, making it much more difficult for the child to interact and build associations with former learning experiences. As a result, Bøttcher and Dammeyer (2016), highlight that they are better able to participate actively in specialised and adapted activity settings. Norwich and Lewis (2001) qualify their position, explaining that whilst the common underlying principles of pedagogic approaches are those used with all pupils, the approaches may indeed look very different in practice, and may be more intense or used more frequently, dependent upon pupils' needs.

The authors' conclusions were largely corroborated by a further study involving fourteen educators of pupils with additional support needs in a collaborative project which explored the interaction between pedagogy, curriculum and teacher knowledge (Lewis and Norwich, 2004). The most widely made point from the contributors was the scarcity of an empirical evidence base that directly related pedagogic strategies to the various SEN areas. This was deemed to be partially attributable to the difficulty and complexity of undertaking systematic evaluation and research. However, all those involved indicated that even when a pupil's categorisation or label informed a specific teaching approach, this still has to be adapted according to individual needs. Thus, even when a 'general differences' position is adopted, individual needs were at the centre of pedagogic decision making. Only two contributors suggested the significance of distinctive group pedagogy for pupils with autism, a medical categorisation which is also used widely in education and which has informed specific teaching approaches (e.g. TEACCH; Mesibov, Shea, & Schopler, 2005). There continues to be little evidence of other aetiology-specific information being applied in the classroom, despite the fact that approximately 60% of children with complex additional support needs have an identified disorder (Oliver, Woodcock & Adams, 2010).

Yet the growing research into children with a specific aetiology (e.g. Dykens, Hodapp & Leckman, 1994) details the strengths and weaknesses of smaller, homogenous groups of children and may have much to offer education in terms of informing teaching strategies which are reflective of a child's cognitive profile. Indeed, research into the better visual processing skills of children with Down's syndrome has informed the 'See and Learn' approach to learning to read, the effectiveness

of which has been demonstrated in research (Abbeduto, Warren, & Conners, 2007).This suggests that there may be an argument to promote a general differences position for children with complex additional support needs whose aetiology results in a distinct cognitive profile. However, the adoption of a 'curriculum for all' and a lack of training on the development of children with complex additional support needs, is likely to result in teachers having less knowledge about the learning profile of these smaller groups of children.

Other recent teaching approaches developed with this group of learners in mind emphasise 'process-based learning' (where the interactive process between staff and pupils takes precedence over the outcome of the task). Such approaches have been informed by research into synchronistic interaction between mother-child dyads (Trevarthen & Aitken, 2001), and also by research into pupils' active engagement (Foreman, Arthur-Kelly, Pascoe, & King, 2004) which suggest that staff should consider individual pupils' behaviours that demonstrate their high level of engagement. There have been a number of studies which have explored the behaviour state of children with profound learning difficulties as a means of identifying factors which support children in reaching an optimal level of alertness for learning (Guess, Siegel-Causey, Roberts, Guy, Ault, & Rues,1993; Foreman, et al., 2004).Yet whilst modifications of the environment, interaction strategies, stimulation strategies and staff training have all been shown to influence the level of alertness, the reliability of the observations has been a core problem in some of the studies (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009), thus affecting the reliability of the results.

The Engagement Profile and Scale (Carpenter, Egerton, Brooks, Cockbill, Fotheringham, et al., Bloom, 2015) is informed by behaviour state research and helps teachers to identify different levels of a pupil's engagement and to build upon those aspects of an activity which enable a child to engage more actively. The intention is to ensure that teachers continue to expand and extend pupils' learning activity, dependent upon their profile. Initial data from the trialling of the scale over three different phases of implementation found that the majority of participating pupils across three different schools showed increased levels of engagement. Again, whilst the scale has been incorporated into the Milestones document (Education Scotland, 2019), there remains issues of reliability of the 'levels of engagement' and there is as yet no wider scale research into teachers' experiences of using the scale to effectively promote pupils' learning.

Despite the current lack of research into its effectiveness, the Engagement Profile and Scale enables teachers to focus on pupils' strengths and interests. Bøttcher and Dammeyer (2016), in the cultural historical model of disability, highlight the importance of planning activities in accordance with a child's motivators and which increase a sense of 'agency.' This is a factor which has not always

been emphasised in educational research but is evident in the parental literature. In the study involving parents of children with brain damage who had made significant progress, participants highlighted how their child's increased sense of agency in an activity led to developmental gains (Lebeer & Rijke, 2002). In a small case study approach into the exploration of the development of the number amongst children with complex additional support needs (Porter, 2005), the author found that the hardest task for the teacher was to devise and develop contexts which sustained the pupil's attention, highlighting the need to base learning opportunities on a child's idiosyncrasies and personal motivators.

2.6.3 Teacher-Pupil Interaction

Intensive interaction is the only most widely known approach which indicates a departure from a target-based curriculum. This is a process-based approach which was initially proposed by Nind and Hewett (Nind & Hewett, 2012) and informed by research into early child-adult communication. The main aim is to improve interaction between adults and people with complex additional support needs with the main learning motivation for both participants being the mutual enjoyment of this. An adult constructs the interaction by allowing the pupil to lead with her/his behaviour, and by responding to this behaviour. The most frequently observed adult responses are to imitate, copy or join-in with what the child does.

Whilst those in adult settings have used intensive interaction as a means of promoting social engagement (Caldwell, 2006), it has also been used in schools to develop pupils' communication skills (Kellett & Nind, 2013). Evaluative studies with pupils have used very small samples, or a case-study approach, and have employed the use of video recording. Behaviours have then been coded, often using eight indicators of social behaviour as developed by Nind (1996). These include interactive behaviours such as looking at a face; socially directed physical contact; eye contact; joint attention; social physical contact. Measures such as the Preverbal Communication Schedule (PVCS) have also been used as baseline measures. Methods and outcomes from school-based evaluative studies are detailed below:

Table 4. Intensive Interaction Research in Schools

Study and Sample	Aim	Methodology and Methods	Outcomes
Barber (2008) 3 pupils with ASD	To explore impact of Intensive Interaction on pupils' communication for 30 weeks.	AB design. Videos coded for 'Indicators of Social Behaviour.'	Decrease in 'no interactive' behaviours, socially directed physical contact, and increase in engagement for all 3.
Kellett (2003; 2004; 2005)	Small scale studies to evaluate efficacy of Intensive Interaction. Case studies with primary aged children. Contributed to larger baseline study.	AB design. Measured percentage incidence of social behaviours and stereotyped behaviours.	Some variability in scores coded. Participants displayed gains in social behaviours but inconsistent and not across settings.
Jones and Howley (2010)	5 children attending interaction programme with ASD and /or learning difficulties. 4 participants in mainstream.	Staff completed semi structured interviews. Parents completed questionnaire.	Staff and parents reported increased communication of children. Staff reported feeling more confident.

Hutchinson and Bodicoat (2015), in their review of the intensive interaction literature, found that methodology shortcomings and small sample sizes prevented any firm conclusions from being drawn. The authors highlighted the difficulty of performing large scale research with people with profound additional support needs, and of evaluating an approach which cannot be delineated into separate components. In addition, although many of the studies employed the coding system developed by Nind (1996), it can be difficult to ensure a shared definition of the behaviour being recorded, especially since there may be no shared understanding of what constitutes improved communication for the individual pupils participating in the research. This suggests the appropriateness of using a case study approach to try to determine the impact of intensive interaction on the teacher-child dyad which ensures that the 'coder' or researcher has an in-depth knowledge of the pupil being observed. Underpinned by a phenomenological approach, Simmons' detailed observation of a young boy, Sam, in different environments over a period of time (Simmons, 2018). Simmons writes detailed 'vignettes' of the pupil's behaviours, taking care not to privilege his own position as the researcher. The role of other key adults in co-constructing the interpretation of Sam's behaviours is deemed essential and the author highlights the importance of conducting ongoing observation with these other adults as a means of making sense of a child's behaviours and also contextualising it.

In the study conducted by Jones and Howley (2010) which included an analysis of teacher views on the impact of intensive interaction, the findings suggested that the intervention had had a positive impact on their practice and that they had gained in confidence. Further research would establish if this is evidenced in practice and if the use of intensive interaction influences teachers' perceptions of a child's ability to communicate and their capacity to make progress. At this stage, it is not known if the use of intensive interaction alters staff's perceptions of a child's abilities or is in fact aligned with their existing beliefs about a child's development. Furthermore, unlike research which has explored synchronistic communication between parent-child dyads (Trevarthen & Aitken, 2001), there has been no analysis of teacher behaviours during intensive interaction to discern if a teacher alters his or her communication in response to the child and as a means of facilitating more synchronistic interaction.

2.6.4 Evaluation of Teaching and Assessment Approaches

There are still very few evaluative studies of other teaching approaches. This is undoubtedly rendered more difficult by the complexity of these pupils' needs and a lack of a clear consensus of what constitutes progress. In a small-scale evaluation of pupils' progress in identified learning targets over a four-year period (Hobbs, 2009), the author noted that pupils' achievements were dependent on extraneous factors such as ill health and therapy interventions. These factors also impacted upon the outcomes of an intensive interaction evaluation (Kellett, 2003). Thus, isolating the impact of teaching approaches on achievement or indeed delineating what constitutes achievement can be challenging.

The recent creation of more rigorous assessment approaches such as 'Quest' (Council for Curriculum, Examinations & Assessment (CCEA) (2009), and Routes for Learning (RfL; Welsh Assembly Government (WAG), 2006), acknowledge pupils' atypical developmental patterns and enable staff to track very small indicators of progress in very early stages of communication and cognition, whilst being cognisant of the fact that achievement in one area (e.g. responding consistently to one stimulus) may not enable them to anticipate the next step in learning (e.g. responding differently to different stimuli). Van Walwyck (2011) in her evaluation of the Routes for Learning materials, found that a more thorough recording system needed to be developed by schools to supplement the Routemap. This could detail the specific stimuli which led to a response, the kind of responses seen, and the setting in which the responses occurred. As yet, there is no research which employs these assessments as baseline measures to track the progress of individual children in key areas.

The South Lanarkshire Framework for Pupils with complex additional support needs, as detailed in the RPL claim (Appendix 2), aims to use the above-mentioned assessment tools and other means of assessment, to help education staff determine a child's attainment and functioning in each of the 4 key areas: communication; self-care and impendence; physical skills and cognition. A possible bank of targets in each of these areas aims to assist staff to assess an individual pupil's functioning. Using an individualised approach to target setting and monitoring is expanded in the recent 'Milestones' document (Education Scotland, 2019) yet the expectation is that a child's functioning can still be framed within the 'Experiences and Outcomes' of the Curriculum for Excellence. In this sense, the mainstream curriculum has been adapted to take into consideration the development of children with more complex additional support needs, rather than starting with their often non-linear and individualised trajectory of development as a basis for what should be taught and how.

As detailed in section 2.4.1, the ICF-CY provides an integrated approach to disability which uses different categories to conduct a more in-depth assessment of a child's needs and how this interacts with the environment to facilitate or hinder engagement in activities. This could inform a more integrated approach to assessment and teaching based on un understanding of a child's functioning and participation in different settings, as well as their aetiology. There is currently a small number of studies in Europe (Portugal and Switzerland) which detail the application of assessment tools which have been developed in order to facilitate the application of the ICF-CY to educational settings. For example, the Participation and Environment Measure for Children and Youth (PEM-CY) uses three perspectives: frequency, extent of involvement, and desire for change to measure participation (Coster, Law and Cadell, 2010.). The PEM-CY also uses parents' views to enable a comparison of views and contexts. However, professionals' views have been mixed about its usefulness as a tool to communicate with parents, seeing both possibilities (involving parents in assessing their children) and difficulties (parents-professional relationship) (Ibragimova, Granlund, and Bjorck-Akesson, 2009). Yet this suggests that the tool can be used as a vehicle for discussion and to make differing views of development explicit.

In Switzerland, the model has been developed into a set of procedures and materials for use in decision-making and programme planning for children/young people identified as having additional support needs. It covers the following areas: environment factors (service and home settings); activity and participation; body functions, ICD classification (disorders/disease)]; development and educational objectives; and appraisal of needs (Hollenweger & Lienhard (2011). According to the authors, the ICF-CY represents an educational perspective where assessment is for learning, a focus on abilities, and future goals. The focus is on learning to participate as much

as possible, not fixing impairments. At the same time, the ICF-CY's biopsychosocial approach means that a child' aetiology or impairment and the impact of this on learning is still very much taken into account when planning for future participation. Whist initial application to education suggests the benefits for further transference to a Scottish setting and a more balanced and integrated approach to assessment, the current very broad and comprehensive categorisations of the ICF-CY still require further revision for it to be used pragmatically and meaningfully with in the Scottish educational context. For example, as shown in the Swiss development, its use for educational purposes requires conceptual developments that relate to educational ideas of wellbeing that go beyond the health-related definitions in the ICF-CY and which include wider connotations that are embedded within the Scottish Curriculum for Excellence.

2.6.5 Summary

Research into teachers' experiences of teaching a child with a disability in a mainstream classroom (Jordan, Glenn and McGhie-Richmond, 2010) indicates that teachers' beliefs may be largely informed by their epistemological beliefs about the nature of learning – defined as 'entity' or 'incremental' beliefs. (Glenn, 2007). Teachers' epistemological beliefs may in turn be influenced by prevalent cultural codes such as the social and medical model of disability. However, these codes can at times differ from those of parents since a teacher's role is informed by prevalent educational policy and pedagogy, including current curricula models. In addition, as is evident in the qualitative study which describes parents' experiences, (Goddard, Lehr & Lapadat, 2000), it is probable that teachers subscribe to dominant cultural codes and narratives which pathologise parents of a child with a disability. This may prevent open dialogue about what can be done at home and school to develop the child's competencies.

The link between teachers' beliefs and their practice when working with children with complex additional support needs has not yet been widely established in research, although research suggests that their confidence is impacted positively by the level of support provided , by training and by their previous experience of working with this group of learners (Avramidis and Norwich, 2010). Furthermore, little is known about affective factors which mediate their responses and about the extent to which teachers show 'insightfulness' towards the pupils with whom they work. Continuing tensions over what constitutes an appropriate curriculum for this group of learners, in addition to a lack of relevant training in the development of children with complex additional support needs, means that teaching staff may be torn between focusing on what they believe to be important aspects of pupils' development whilst adhering to a curriculum and educational policy that has been devised primarily with mainstream pupils in mind. This makes it difficult to obtain a

shared view amongst teaching staff about what constitutes progress for individual pupils and what strategies and assessment methods they should be using. Whilst there are a small number of specialised teaching approaches (e.g. intensive interaction), there is also a need for further evaluative studies to determine if the use of such methods or if recently devised curricula (e.g. The Bridge School, 2013) shape teachers beliefs about development and, consequently, have a positive impact on a child's progress. Such studies may eventually inform the views of those involved in curriculum planning for this group of learners.

2.7 Teacher-Parent Views – Comparative Studies

The literature suggests that understanding ways in which conceptualisations of development influence parental responses and the education decision making process for children with complex additional support needs may help to arrive at a shared understanding of progress, or at least to better understand the potentially differing perspective of parents and education staff. However, there are very few studies which compare parent and teacher beliefs and responses to this group of learners. This section details two such studies - both of which employed qualitative methods - (Bøttcher; 2014, Lalvani, 2015).

In the qualitative study conducted by Lalvani (2015), semi-structured interviews were used to ascertain similarities and differences in the interpretations of 32 parents and 32 teachers regarding pertinent issues in both educating and parenting a child with disabilities. The study revealed broad conceptual differences in interpretations of disability between the two groups. Whereas parental conceptualisations were more representative of the social model of disability and highlighted cultural issues of stigma and marginalisation, teachers' views were more aligned with the medical model of disability and suggested that they understood disability in terms of the level of physical or cognitive impairment. Parents revealed more negative reactions to the use of specific labels pertinent to a disability. Conversely, regardless of the number of years' experience, teachers viewed labels as helpful in informing a suitable educational placement or learning goals. This runs counter to the current focus on a 'curriculum for all', which places less emphasis on the use of labels, and which can in turn, hinder appropriate and individualised planning.

In a three year research study conducted by Bøttcher (2014), video observations of lessons, team meetings, and interviews with teachers and mothers were conducted in order to explore how the knowledge exchange between parents and school staff for 2 boys with cerebral palsy was translated into practice and led to developmental consequences for both boys. Central to the tenets of cultural-historical dialectal thinking which categorises Bøttcher's research, the children and their caregivers were viewed as co-creators of the child's development. Although both participating

mothers were highly motivated to influence their child's developmental conditions, one mother had far more success than the other. Further analysis of the documentation suggested that this was because the school staff of one of the boys had adapted the learning environment and activities based on an assessment of his needs and his behaviours which included screaming, crying and lashing out. Bøttcher reflected that this pupil, David, *'afforded'* a response from staff - (affordances are defined as functionally significant properties in relation to individuals and their personal history and intentionality within cultural-historical environments; Bang, 2009). It can also be hypothesised that this teacher held an 'interventionist' view of disability (Jordan, Glenn & McGhie-Richmond et al., 2010). These adaptations accommodated David's needs and contributed to David's active engagement and to his subsequent progress.

Conversely, when the observations showed that the other pupil, Oliver, was not able to participate actively in organised activities, there was no response from staff. Whilst David exhibited behaviours such as crying in response to his inability to engage, Oliver was described by Bøttcher as remaining silent. This may have influenced staff responses to him since he may have been perceived as not requiring a response. It also indicates that staff did not carry out further analysis of what these quiet behaviours might signify. In her conclusion, Bøttcher and Dammeyer (2016) suggest that it is the extent to which teachers perceive the child as an actor who 'affords' responses from staff that appear to affect the extent to which the school creates appropriate activity settings for the child. This implies that the child's presentation and the teacher's understanding of this (e.g. if the child is considered by a teacher to demonstrate agency) exert more influence on teacher responses than the information shared by parents. Perhaps, if a teacher interprets a child's behaviours as demonstrating agency – and thus reinforcing cultural norms – they are more likely to adopt an interventionist approach when supporting the pupil's progress.

2.8 Conclusion and Next Steps

Because of the individualised trajectory of children with complex additional support needs and the use of categorisations which change over time and in accordance with prevalent policy and pedagogy, there continues to be no common conceptual understanding of their development, especially in educational settings. The literature review demonstrates that parents' and teachers' views about the development of children with complex additional support needs are informed by cultural notions of typical development and by dominant and sometimes conflicting models of disability. For parents, the difficulty of understanding the development of a child whose trajectory is not aligned with that of typically developing peers is reinforced by cultural emphasis on a child's sense of agency, and ability to communicate. The research also suggests that the way in which

teachers perceive a child can lead to different situations of development by facilitating or impeding the transfer of knowledge from school to home (Bøttcher, 2014). This is compounded by the adoption of a general curriculum framework, a dearth of specific teacher training and a lack of evaluation into specialised teaching approaches, which result in teacher practice which is not always based on a common understanding of what constitutes progress for the individual child.

It has yet to be established if there is a time throughout a child's education when teachers' and parents' beliefs are aligned, or whether the influence of opposing models of disability lead to fundamental differences in views. What is lacking from the literature review is research which not only compares the views of parents with those if education staff, but which looks explicitly at the earliest stage in a child's education – the preschool years. Whilst research considers teachers' views of supporting children with additional support needs and their views of inclusion, no research was found which includes nursery staff - and in particular nursery keyworkers- and which focuses explicitly on those learners with complex additional support needs. Bøttcher and Dammeyer (2016) propose that a platform needs to be built between parents and teachers in order to minimise developmental incongruence. However, Lalvani (2015) questions whether a true partnership can exist if feelings of pity or pathological views of the family prevail and are exacerbated by cultural norms. Such views are incongruous with relationships of equal status and are not conducive to collaboration. Indeed, Bøttcher and Dammeyer (2016) offer no practical suggestions for ways of working towards a shared understanding of progress for individual children.

There is also a dearth of studies which explore parental views of development of nursery aged children with additional support needs. Do some parents of children with complex additional support need demonstrate what is coined in the research as' insightfulness?, (Oppenheim &Koren-Karie, 2002), and an ability to maintain a complex view of their child and possess an understanding of their strengths and weaknesses? If so, does it follow that more 'insightful' parents adapt their responses in accordance with the needs of the child and thus see the impact of their practices on their child's development? Is it probable, too, that teachers and nursery staff with a more individualised understanding of a child's development have beliefs similar to those of insightful parents? Does this shared understanding promote practices which correspond with the pupil's needs and thus lead to progress? These are questions which have been hitherto unanswered.

CHAPTER 3 PROJECT II

Parents' and Nursery Staff Conceptualisations of Development for Young Children with Complex Additional Support Needs

3.1. Introduction:

The literature review indicated a lack of clarity amongst parents and nursery staff regarding the developmental trajectory for young children with complex additional support needs and a tendency to adhere to cultural norms of progress and to notions of inclusion which do not necessarily recognise or address difference. This focus on a linear trajectory of development may be more evident in the nursery setting, when parents have only recently learned of their child's diagnosis and when the nature of their needs is still evolving. The review also highlighted an evolving picture regarding both categorisations and the curriculum for children with complex additional support needs. These are informed by dominant social norms and pedagogical practice and are compounded by a lack of empirical evidence of teaching approaches which best promotes the progress of young children with complex additional support needs. The following outcomes of the literature review informed the aims and methodology of the final study, Project II:

- Despite the prevalence of ecological theories of development in educational psychology practice, the literature suggests that contextual factors are not necessarily taken into account in practice when considering the progress of a child with complex additional support needs in the early years. Although there have been changes to take into account a child's non-linear progress (The 'Milestones' document, Education Scotland, 2019), the curriculum continues to be based on a mainstream model (The Curriculum for Excellence).

- There is still a lack of research into the effectiveness of teaching strategies which promote the development of children with complex additional support needs. There exists dubiety over whether teachers should use specialised teaching approaches which have been developed to support the needs of a particular group (e.g. children with ASD) or whether strategies are based primarily on those used to support the progress of typically developing children and are adapted to meet the needs of an individual child.

- There are very few studies which compare parent and teacher beliefs and responses to this group of learners (Lalvani, 2015; Bøttcher & Dammeyer, 2016) and no studies could be found which compare parents' and staff views at the earliest stage of a child's education – when the child is at nursery.

- Although there are studies which explore parent and child interaction for young children with disabilities, there were far fewer studies which explored parental beliefs about their child's development (Sigel, 1992) and the strategies they employ to promote their child's progress.

- The literature also indicates that parents are less likely to have achieved resolution of their child's disability in the earlier stages of their child's development, when they are still embedded within the medical context (Landsman, 2005) and have frequent contact with medical professionals. This suggests that parents at this stage may be more invested in the medical model of disability, which focuses on a child's impairment and the extent to which his or her development deviates from 'the norm'.

- It may be probable that nursery staff beliefs about the development of this group of learners are more informed by current curricular models and by early years' policy and pedagogy, underpinned by cultural norms of development. However, there is a dearth of studies which include nursery staff who are supporting children with this level of needs in the early years and explore their views of development.

3.1.1 Aims of the Study and Methodology

The aim of the study was to obtain parents' and nursery staff views about the development of young children with complex additional support needs and to explore how their lived experiences of supporting a child and the wider cultural context had contributed to their conceptualisations of progress. The focus was therefore on understanding the key features of the child's development as perceived by individual parents and nursey staff and to obtain a clearer understanding of the factors which had influenced their views.

The research questions were as follows:

- How do parents and nursery staff understand the development and progress for young children with complex additional support needs?

- How are these conceptualisations of progress constructed over time?

- What different contextual factors influence parental and nursery views of progress (e.g. the child's presentation and the wider cultural context)?

- How do participants' views of the child's progress inform their interaction with the child and the strategies that they use to promote the child's progress?

- How are conceptualisations of progress for a young child with complex additional support needs negotiated between parents and nursery staff in the nursery setting?

Consistent with the social-constructionist epistemology of the study, a qualitative research design was used to explore how parents' interpretations of their child's development compare with those of nursery staff and with dominant narratives of progress. Data gathered from Semi-structured interviews and from two focus groups of parents and nursery staff were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). IPA's focus on the in-depth examination of specific phenomena means that it is suited to investigating novel areas of research such as this one. Research using IPA also tends to deal with significant, sometimes life-transforming, events or conditions. Trying to make sense of the development of a child with complex additional needs is an especially emotive experience for parents, and one which potentially places nursery staff out with the realm of their skill set and training. In addition, IPA allows for rich descriptions of how individuals think and feel about their experiences and the challenges that they have faced. A qualitative study that focuses on the experiences of those supporting a child with complex additional support needs and how they try to make sense of their development is important in contributing to our understanding of the factors that influence individual views and in trying to ascertain if it is possible to achieve a shared understanding of progress. It was hoped that this could help to inform practice in the nursery setting and facilitate closer collaboration between parents and staff.

3.2 Methods

3.2.1 Participants

Purposeful sampling was employed to select the most appropriate participants to answer the research questions. This involved identifying parents and teachers of young children with complex additional support needs attending nurseries within my place of work at that time – the local authority of South Lanarkshire

After ethical approval had been obtained from the University of Dundee, names of children and parents were identified through liaison with the three other Early Years Lead educational psychologists in the service. It was also hoped to obtain a representation of the differing nursery provisions across the authority (e.g. mainstream nursery classes attached to a school and supporting children in their ante pre and preschool year; standalone authority nurseries supporting children from aged two upwards; private 'partnership' nurseries; the single identified Additional Support Needs nursery in the authority which supported children with a range of identified additional support needs.)

Further discussion with the nursery managers of the identified nurseries took place via telephone to explain the purpose of the research and to establish the appropriateness and willingness of the parents and nursery staff of the children selected. It was agreed that the parents of two children

who had been identified would not be approached since their children were currently in hospital. Heads of establishment approached identified parents and nursery staff in the first instance and then gave their consent for me to approach members of the nursery staff. Once verbal consent had been obtained, an information sheet and consent form were sent to the participants: nursery staff, the heads of establishment and parents. If parent participants had further questions, I spoke with them again to explain the contents of the information leaflet more fully. A follow up phone call with parent and nursery staff participants confirmed the time, date and suitable venue for the interview.

As far as was possible, it was hoped that the sample would be representative of young children with complex additional support needs across the authority who demonstrated associated physical and/or health difficulties and with different aetiologies and diagnoses. This was restricted by the small number of children with this level of needs within the authority and attending nursery. The final sample comprised of nine parents (including one couple) of eight children (two boys and six girls) who had been identified by nursery establishments and educational psychologists as having complex additional support needs, and nine corresponding keyworkers (including the Depute of establishment and keyworker in one nursery) from each of the children's nurseries. Three of the eight identified children discussed had an autism spectrum disorder (ASD) diagnosis. Although this forms a larger percent of the sample, it is also representative of the number of children with an ASD diagnosis within this group of learners. For example, Brugha et al.; 2012, found between 31% and 35.4% of people with a learning disability are autistic.

I had initially wished to interview the parents of young children between the ages of two and three years old, based on the fact that it was considered more appropriate to involve parents prior to their child's transition to school. Indeed, research documents the emotional and practical impact of this transition on a family of a child with this level of needs (Ytterhus, Wendelborg & Lundeby, 2008). However, the final sample involved parents of children between the ages of two and four and meant that one child was at school by the time the two focus groups took place. Significantly, however, this enabled his mother to reflect upon on the impact of her son's transition to school on her views about his development. This then contributed to the final analysis

The table below offers further information about the participants and each child discussed and demonstrates the relationships and connections between the parent and nursery staff participants. The table also serves as an 'aide memoire' to which the reader can refer and provides a context for the in-depth analysis of the themes which emerge from the data. It should be noted that all names used are pseudonyms.

Table 5. Information about Participants and the Children Discussed in the Study

Parent Participant	Nursery Staff Participant
Lucy's daughter, Maddie, is two years old and has recently received a diagnosis of a very rare genetic syndrome which results in learning difficulties, physical difficulties, and other complex health issues. The diagnostic process only started after one year when it became evident that Maddie was not making the progress that would be expected of a child her age.	Pauline works in a large stand-alone nursery in the authority where she has recently become the keyworker for Maddie, aged two, who has a rare genetic disorder. Pauline has only recently moved to this authority. She has some previous experience of working with children with autism and did two weeks of supply work in the ASN nursery, where she supported children with profound needs and complex health issues.
Hannah has a four-year-old daughter, Emily, with Down's Syndrome who is at the end of her pre-school year at a stand-alone nursery within the authority. She has secured another deferred year at nursery before attending school.	Margaret has over thirty years' experience of working as an early-years worker in nurseries. She currently works in a large stand-alone authority nursery where staff have supported several children with a wide range of additional support needs. She is currently the keyworker for Emily who has Down's Syndrome.
Jackie has a daughter, Olivia, with severe autism. She received her diagnosis at the age of two. Jackie thinks this happened earlier because of her older son, who also has autistic characteristics although does not demonstrate the same extent of difficulties as his sister.	Tricia works in a nursery class which forms part of a primary school within the authority. She previously worked in a large stand-alone nursery within the authority where she gained a lot of experience of supporting children with additional support needs (ASN). Tricia has been the keyworker for Olivia since she started the nursery at the age of two.
Jennifer's son, Joe, is four and has recently been diagnosed with autism. Her understanding of her son's development has been aided by her experience working as an early year's worker in one of the authority's stand-alone nurseries (the nursery which Joe now attends) where she has supported other children with ASN.	Vicki is the youngest member of staff in a larger stand-alone nursery. She is the key worker for Joe who has ASD. She has sought out information about ASD from the internet and from personal reading. She also completed a course on ASD in her previous job and has personal experience of ASD outwith the work environment.
Fiona is the mother of a son, Tom, with Cornelia de Lange syndrome. Tom received his diagnosis after a year of assessment. Tom has just finished attending a partnership nursery (a private nursery) where Fiona is aware that staff have had no previous experience of supporting a child with this level of needs.	Mary works in a private nursery which has a partnership arrangement with the authority. She has been the keyworker for Tom, who has Cornelia de Lange syndrome, for the last 2 years. Margaret has had no previous experience of supporting a child with this level of needs.

Sylvie has a three-year-old daughter, Daisy, who suffered Hypoxic Ischemic Encephalopathy (HIE) because of a traumatic birth and who has mild right hemiplegia and learning difficulties as a result. Daisy has been attending a nursery class within a mainstream school nursery where Sylvie had formed a very positive relationship with her previous keyworker, Una, whom she describes as being one of the only other people to understand Daisy and her learning needs.	Una and Ainsley are the keyworker and depute of a nursery class within a mainstream primary school. Ainsley attended the beginning and final ten minutes of the interview, and the analysis is largely based on Una's responses. Una was previously Daisy's keyworker before she transitioned to the room for children between the ages of three to five and to a new keyworker.
Pam and Craig are parents to Ruby, who has Rett syndrome. Ruby was resuscitated for sixteen minutes at birth. She was diagnosed close to her first birthday, following a seizure and increasing concerns about her development.	Lizzie has been working at the only authority Additional Support Needs nursery since she qualified as an early year's worker five years ago. She has been the keyworker for Ruby who has Rett syndrome.
Lesley-Anne's daughter, Leah is three. She has autism and has only recently received a diagnosis. Leah has recently transitioned to a different room in the ASN nursery and to a different keyworker.	Jane is a more experienced member of the team at the ASN nursery and was the previous keyworker for Leah who has ASD. She has participated in training in the South Lanarkshire Framework for supporting pupils with complex additional support needs.

3.2.2 Ethical Considerations

The literature highlights the fact that parents of a child with a disability may experience stress and loss, exacerbated by dominant discourses of disability which may pathologise parents (Lalvani, 2015) and which make it difficult for children with severe disabilities to engage in the same activities as their typically developing peers (Bøttcher & Dammeyer, 2016). For this reason, it was predicted that parents would potentially find it difficult to talk at length about an emotive subject which they may not have consciously reflected upon or which they may not have discussed at length with professionals.

An ethics proposal was submitted both to the University of Dundee Ethics Committee and to the South Lanarkshire Council research team, the local authority where the research was conducted. (Appendices 4.1 and 4.3). An overview of the interview questions was provided to the participants in the information leaflet (Appendices 4.4. and 4.5) prior to the interview to enable them to reflect upon their responses and to consider the potential emotive aspect of some of the questions. Parent participants chose the time and location of the interview, to enable them to talk at length in a setting

in which they felt comfortable. I aimed to provide a non-judgemental setting, and as far as possible to promote an equal participant-researcher relationship. It was hoped that the opportunity to talk at length about their thoughts and feelings about their child's development would enable parents to formulate their thinking more clearly, or to feel listened to. It was also highlighted to parents that appropriate means of support would be signposted, and the opportunity to discuss these issues further would be available, if the need arose. This was made easier by the fact that I worked within the authority.

In my role as senior educational psychologist and as chair of the Early Years Multi Agency Team in one area of the authority at the time the research was conducted, I was known to three of the parents and four of the nursery staff participating in the research. I discussed this with the parents and nursery staff at the beginning of the process to ensure that they felt confident about speaking openly throughout the interview. I also asked the Heads of the nursery establishments to discuss this with the respective parents when the opportunity to participate in the research was first broached with them. Whilst I had forged a very positive relationship with those parents with whom I had worked with closely, I was known to all participants, primarily in my role as an education professional. This would undoubtedly inform responses from both the parent and nursery staff participants. Although educational psychology promotes the use of solution-focused approaches which support others to generate their own solutions, the core role of providing consultation and offering advice can create a power differential which was acknowledged in the context of the research study.

When two focus groups were planned after the original individual interviews, further consideration was given to the sensitive nature of the themes to be discussed and to the potential power differential between staff and parents. As with the initial interviews, a letter and information leaflet was sent to each of the original participants (Appendices 4.7, 4.8 and 4.9). This detailed the main themes that had emerged from the analysis of the interviews. It was originally intended that each of the two groups would include parents and nursery staff not known to each other, to enable them to speak more openly. However, since only half of the original participants indicated that they wished to or were able to participate, this was not possible. Instead, they were informed in advance of the make-up of the group and if their child's nursery keyworker would be in attendance - thus giving them the opportunity to withdraw if they felt that the setting would not encourage open discussion. No participants withdrew at this point.

3.2.3 Interviews

The initial collection of data occurred via face-to-face interviews between me and the participants; the nine parents of individual nursery children (aged two-four years) with complex additional support needs and with nine individual nursery staff who were the keyworkers for the respective children. The interviews took place in a private room at the nursery (parents: five; nursery staff: seven); and in the participants' own homes (parents: four; nursery staff: one). These lasted between thirty-five and ninety minutes. Participants were asked to reflect upon what they believed to be important aspects of development for the child and the strategies that they were employing to promote their progress. A semi-structured interview was employed to ensure that the research questions were addressed, whilst enabling parents to tell their stories and permitting emerging and unexpected themes to occur. Interview schedules were short, starting with more specific questions to obtain further information about the child's diagnosis but moving to non-directive open-ended questions. Initial questions focused on biographical and background information such as the child's name, age, nursery, diagnosis. These served to relax participants, develop rapport and provide a context from which to begin to explore the focus of the interview. Open-ended questions were then used to ensure some consistency in data collection and to allow for comparative data analysis (Appendix 3).

Prior to conducting the interviews, a mother of a child with complex additional support needs known to me read through the proposed interview schedules and confirmed the appropriateness of the chosen questions and suggested possible adaptations. The interview schedule was not followed in any strict or rigid way and was conducted in accordance with the responses provided. At times, I summarised answers to check understanding and asked further questions in order to clarify a response or to elicit information about how the participant felt about what they had said.

All interviews were audio recorded with the permission of the interviewee. Audio recording enabled a verbatim transcription of each interview to be made after the interview. Following each interview, I made field-notes and listened to the recording for a second time.

3.2.4 Focus Groups

Following the recording transcription and analysis of individual interviews, two focus groups were employed to which original participants were invited. These took place between seven and twelve months after the initial interviews. The aims of the focus groups were to present, discuss, and confirm or disconfirm themes which had emerged from the interview data. It was hoped that this would increase the validity of the original findings by involving the participants actively in the process. Conversely from the individual interviews, the accounts offered in a group setting were

likely to be shaped not only by my questions but also by the shared experiences amongst participants supporting the progress of a child with complex additional support needs, and by the nature of pre-existing relationships between parents and nursery staff (Palmer, Larkin, de Visser & Fadden, 2010). It was also hoped that the composition of staff and parents within one group would enable a further exploration of the impact of context and roles on individual views.

The two focus groups were of mixed composition (both nursery staff and parent participants). Although all original participants were invited to attend and were sent a letter and a choice of dates, the final two groups were composed of two parent participants, and two nursery staff. Time constraints made it difficult to ensure that all initial parent participants were able to attend since the children still attended ongoing medical appointments. In addition, two of the nursery staff were unable to attend at the proposed time because of work commitments; one nursery worker had left her post since the initial interview whilst another was on annual leave.

As facilitator, I presented each of the five main themes from the original data analysis using a visual infographic (Appendix 5.2) and used this as a framework to inform the discussion. In addition to the common themes, I highlighted the diversity of views which had emerged. This was then followed by prompts and open-ended questions which offered opportunities for all participants in the group to engage with the issues under discussion and to explain the extent to which their individual experiences and context had informed their views; if they felt their views were accurately represented in the themes, or if any of their original views had changed. Throughout the focus group, I monitored the discussion; listening to responses, following up interesting points and supporting quiet participants to speak in order to increase reflexivity and promote a supportive environment. Participants were also asked to generate ideas about how the findings could be translated into practice to facilitate a shared understanding of a child's progress.

3.2.5 Method of Analysis

I wished to adopt an interpretative approach to the analysis of data that is not possible using a more general thematic approach. Since the language used to describe disability is informed by the two dominant models of disability and both mediates and constructs how disability is perceived, I initially reflected on the use of Discourse Analysis as an appropriate method. Discourse Analysis argues that it is through the shared, mutually agreed-on use of language that meaning is created (Chandler, 2002). However, as explained above, rather than focusing primarily on how discourse shapes understandings of development and maintains social norms, I wished to further explore participants' lived experience; how understandings of the development of children with complex additional support needs informed their responses and interactions with a child and the strategies

they used to promote their progress. For this reason, I chose Interpretative Phenomenological Analysis (IPA) (Eatough & Smith; 2008; Smith, Flowers & Larkin, 2009) in order to detect main themes and subthemes. IPA, influenced by hermeneutics (Eatough & Smith, 2008), enabled a further level of analysis than Discourse Analysis would permit. It is phenomenological in its detailed examination of personal lived experience of participants and in exploring how participants make sense of their experience. It is also interpretative in recognising the role of the researcher in making sense of the participant's experiences. This was especially important for this study since I was aware that both my job as an educational psychologist and experience as a mother would inform my analysis. IPA also provided me with a framework and a process for data analysis consistent with the study's theoretical underpinnings. At the same time, the process of analysis remained flexible and open to adaptation.

IPA is also informed by the theoretical perspective of symbolic interactionism (Smith, 1996) which focuses on how individuals construct meaning within both a social and personal world. Thus, IPA *'endorses social constructionism's claim that sociocultural and historical processes are central to how we experience and understand our lives, including the stories we tell about these lives'* (Eatough & Smith, 2008: p184). This includes exploring the co-constructive qualities of individual contributions, within the context of the group discussion, e.g. the role played by the facilitator, and the influence of the group's roles and relationships on individual contributions. Further reflections on how a participant's cultural world informs their views was particularly important for this research study since conceptualisations of disability, and whether children with disabilities are enabled or disabled, is informed by current cultural notions and models of disability. The study thus aimed to unpick participants' understanding of the development of children with complex additional support needs in a specific culture (in nurseries within a Scottish local authority) at a moment in history.

3.2.6 Rigour of the Research Process

Although my choice of qualitative methodology was based on my epistemological position and the purpose of the study, I was aware that such research is frequently criticised for lacking scientific rigour and for a process of analysis that lacks transparency (Noble and Smith, 2015). These views are reinforced by the fact that there is no common and accepted agreement about the standards by which research studies should be judged. Yet, the philosophical positions and aims of qualitative research require frameworks for establishing validity and reliability which are markedly different from those employed in quantitative research. For example, Noble and Smith (2015), cite Guba and Lincoln (2005), as offering alternative criteria for demonstrating rigour within qualitative research, including: truth value, consistency and neutrality, and applicability. Yardley, too, (2000), recommends four principles of enhancing the validity of

qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance.

Definitions of validity and reliability as relevant to qualitative methodology are detailed below in the left-hand column. How these principles informed the study and ensured that the method of analysis was both transparent and employed with consistency are detailed in the right-hand column. More information is then provided below.

Table 6. Validity, Reliability and Generalisability of Qualitative Methods Chosen

Validity **The precision in which the findings accurately reflect the data.** **(referred to by Guba and Lincoln (2005) as truth value:- recognises that multiple perspectives exist).**	• I have both knowledge of and experience of employing IPA • I clearly presented participants' perspectives and included verbatim descriptions of participants' accounts to support findings • I conducted ongoing critical reflection of methods to ensure enough depth and relevance of data collection and analysis • I sought out similarities and differences across accounts to ensure different perspectives were represented. • I demonstrate clarity in terms of thought processes during data analysis and my interpretations of these. • I invited participants to attend a focus group to present emerging themes from the findings and to enable them to comment on these and on whether they reflected their experiences and interview responses.
Reliability **The consistency of the analytical procedures, including accounting for personal and research method biases that may have influenced the findings.** **Relates to the 'trustworthiness' by which the methods have been undertaken and is dependent on the researcher maintaining a 'decision-trail' (Guba and Lincoln, 2005).**	• I have explained how the methods undertaken and findings are intrinsically linked to my philosophical position, experiences and perspectives • I provided a clear description of the research process to participants both verbally and in information leaflets • The semi-structured audio-recorded interviews allowed for repeated revisiting of the data to check emerging themes and to remain true to participants' accounts. • I make reference to personal experiences and viewpoints that informed my analysis and accounted for personal biases • I demonstrated a clear decision trail and ensured interpretations of data are consistent and transparent. This involved manual transcription of interviews and focus groups.

	• I conducted manual analysis in accordance with that recommend by Smith, Flowers and Larkin (2009), and then through the use of NVivo as a way of corroborating findings and further triangulating data
Generalisability **The transferability of the findings to other settings and applicability in other contexts.**	• I carried out data triangulation by conducting two focus groups after the individual interview. This helped produce a more comprehensive set of findings. • In the final analysis, I gave consideration to whether findings can be applied to other contexts, settings or groups. • Further consideration is given to the practical implications of the findings in educational settings

Interviews and the focus groups were transcribed manually after being listened to for a second time. The framework for analysis, recommended by Smith, Flowers and Larkin (2009) was followed. This involved several close readings of the first transcript, during which comments of significance and initial codes were noted in a margin. During the next stage, these initial comments were used to contribute to deeper analysis and emergent themes were then written in a second margin. Because of the significant amount of interview data, the interviews were analysed once again using NVivo software and employing the themes that had been extrapolated from the manual analysis. This allowed me to check for any comments of significance that had not been highlighted as a result of the manual analysis, and to verify the number of times a theme, key phrases or vocabulary were highlighted across transcripts, as well as clarifying once again the connections between themes. The data reduction and analysis process are detailed in Appendix 6.

At various points, codes were relabelled, split or merged, as necessary. Many themes emerged from the individual transcripts and when the same themes appeared in at least half of the other transcripts, they were categorised as being recurrent. This was to promote an idiographic perspective but, at the same time, to gain a wider perspective across the transcripts. Themes from parent interviews were grouped into over-arching themes and given a label. The same process was repeated for the nursery staff interviews. In order to help to elicit key similarities and differences between parent and nursery staff responses, the two sets of comparative over-arching themes were integrated together. Finally, a list of comparative themes was compiled. This formed the basis of the narrative report, including quotes and extracts from the participants. The extracts were selected because they presented the essence of recurrent themes or because they provided powerful examples of a theme. Quotes were also included if they provided a unique example of a theme or reflected a contrast in opinion to that of the other participants.

The same process of analysis was undertaken when analysing the focus groups, although in this instance, the themes from the interviews formed the basis of the discussion and informed the questions posed to the participants. The content was thus analysed in accordance with the existing themes, with further exploration of how these were expanded upon or were less prevalent within the context of the group discussion. Any new subthemes which emerged were also analysed. In order to take account of the influence of both context and social grouping on individual responses elicited, the data was analysed using some of the prompts in the protocol created by Palmer, Larkin, de Visser and Fadden (2010) for analysing focus groups. This includes: 1. Positionality: Exploring the role played by the facilitator, monitoring questions, permissions, and redirections, etc. 2. Roles & Relationships: examining references to other people: E.g. What roles and relationships are described? What sorts of meanings and expectations are attributed to these relationships? 3. Adaptation of Emergent Themes: Returning to the emergent themes from initial interviews and adapting them according to the analysis of the focus group data. E.g. what experiences are being shared? What are individuals doing by sharing their experiences?

3.2.7 Role as Interviewer and Facilitator

IPA situates the researcher as central to the research process, such that observations made during analysis of the participant accounts, *"... are necessarily the product of interpretation."* (Willig, 2012, p53). The way in which the researcher understands the participant's experience of the phenomenon under analysis and the meanings participants make of this, are influenced by the researcher's engagement with and interpretation of the participant's account. IPA is both phenomenological and interpretive and necessitates researcher reflexivity throughout (Smith et al; 2009). This requires reflection at each stage of the research process.

I have had had significant experience of conducting research interviews in both my role as an educational psychologist and in my previous post as a research assistant and former Masters student. As an educational psychologist, I frequently conduct interviews in order to gain further information about a child or young person, or as a means of obtaining the perspectives of children, staff and parents as a key part of an ecological assessment. I also carry out interviews for therapeutic purposes when working with young people. I was aware that these different purposes and contexts could inadvertently inform my style of questioning in this research setting and influence my engagement and interpretation of participants' accounts. After the transcription of the interviews had been completed, I undertook further analysis of my questioning to attempt to ascertain the extent to which my interviewing style may have informed participant's responses.

I employed paraphrasing as a means of listening actively to responses. However, upon further analysis of the interviews, I deemed that there were a small number of occasions when I had summarised themes from a section of dialogue too prematurely, and prior to any formal analysis. This is because I was very aware of the emotive content of the interviews. The reactions of the parent participants also resonated with my own personal experience of having had a young son with a profound disability. There were several occasions when I demonstrated the full extent of my empathy, rather than putting this aside. For example, I gave several participants options as a means of incurring a response when I interpreted their silence as their difficulty in responding to an emotive question. I thus made assumptions about their answers – when I thought the response may be too painful to deliver. In this sense, there were some occasions when I jumped in too quickly or used 'over empathic' questioning (Smith, Flowers & Larkin, 2009) by interjecting with phrases such as e.g. *'I imagine that is hard.'*

It also may be the case that I presumed that their reactions or responses would mirror my own, rather than taking time to check this out. This could have inadvertently influenced participants' responses and 'put words into their mouth', rather than allowing them time to reflect upon their own feelings and reactions to certain situations. However, my use of questioning was also based on my assessment of participants' nonverbal gestures and responses, and on my own professional experience of employing active listening and therapeutic approaches. This understanding of participants' lived experiences, coupled with my own professional skills, may have in fact prompted more open dialogue about a topic that is very sensitive in nature.

Finding a comfortable research persona was not always easy. Three of the parent participants and four of the nursery staff knew me in my role as an educational psychologist. I did not always put aside certain habits such as exercising therapeutic capacity; offering advice when it was sought; or sharing personal experience. However, in some instances, the positive relationship that I had previously formed with these participants in my role as an educational psychologist facilitated the conduction of the research interview and often resulted in participants talking freely and at length without me having to first attempt to establish a comfortable listening space. It also meant that for participants, my relationship with them made it easier to encourage them to tell their own stories rather than giving more generic and impersonal accounts.

The two focus groups provided a means of obtaining further clarification about the impact of my role and relationships on participants' responses. In accordance with Yardley's framework for increasing the validity of qualitative research (Yardley, 2000), it was hoped that this would increase transparency and reflection. I was also aware that any reflections would be nested within the set of

relationships between parents/nursery worker; parents/educational psychologists, or parent/parent. For this reason, I was explicit about the impact of my own differing roles on how I both conducted and analysed the interviews. During the first focus group, I chose to explain not only my role as a researcher and educational psychologist, but also to inform the participants that I had been mother to a young son with cerebral palsy. I found this difficult to do since it is not information that I share with parents when I am working as an educational psychologist. This decision had been the result of discussion in supervision when it had been agreed that this level of personal information could serve to explain one of my main drivers for the research project, whilst increasing both transparency and authenticity. However, I was also aware that this level of personal information would not necessarily contribute to eliminating any perceived power differential since all the participants were cognisant of my professional role. Indeed, when transcribing and listening to the data from the first focus group, it was evident to me that I presented this information quickly with little chance for the parents and nursery staff to comment.

Upon reflection, I was concerned that the participants may have felt that this information would detract from their own stories and shift the emphasis from their experiences to my own. It was also difficult to ascertain the extent to which this knowledge served to reduce the power differential or elicit further information from the participants. Interestingly, only one participant responded directly to my personal account:

'That kind of helps you understand, doesn't it'?' (Jackie, Olivia's mother).

The dialogue continued with participants detailing their own experiences. In the second focus group, I did not refer to my personal situation since I reflected that my own reluctance to divulge this information may hinder the flow of dialogue. However, another nursery keyworker participant linked the parents' experiences to her own, referring to her own adult son's illness. This suggests that the focus group provided a safe environment in which she felt able to compare parents' difficult and emotional experiences to her own.

Another means of increasing transparency and validity was to ask participants about their own reactions to the initial interviews; if it had enabled them to reflect on their views and to articulate their own thoughts and feelings and if the experience had affected them emotionally. I also asked whether my relationship with several of the participants as their child's educational psychologist had impacted on their ability to respond freely. This was of importance since an aim of the research was to explore how educational psychologists can talk with both parents and staff as a means of minimising developmental incongruence and enabling those around the child to share their views about the child's progress.

All four participating parents indicated that the interview process had been emotional:

'I feel that when you go to some doctors, it's just a case of… I can't be bothered reading the notes so… You know? But the interview was done in a compassionate way but, it was quite upsetting. For me, it was'. (Hannah, Emily's mother).

'It's emotional erm but I find it, it's really good. I went home and questioned myself a lot.' (Lucy, Maddie's mother)

'It was quite good as well because after it, you kind of think, "Oh, right, okay. I didn't realise that I had said something that probably I hadn't thought of before.'(Lucy, Maddie's mother).

'I didn't feel uncomfortable. I feel quite comfortable and you prepared us for the questions you were going to ask.'...I was quite happy. It was nice to actually to have somebody to listen to you and like be able to give your views and all that.' (Jackie, Olivia's mother).

'There are certain things you can't say maybe to family members or whatnot and then somebody else who you don't really know too well ... you can kind of .. let it out.. I suppose'(Jackie, Olivia's mother).

'There was also… I think things came up that probably you wouldn't say to other people. You don't sit there and tell the consultant and things like that. Basically, they just ask you the basics so, you want a bit more depth.'(Hannah, Emily's mother).

The quotes above indicate that the parents' experience of the interviews had been largely positive, albeit emotional. They reported that they had felt listened to and it had it enabled them to talk openly and in more depth, or to reflect upon issues which they had not had the opportunity to consider prior to this. Their responses also indicated that the interview setting, the preparation beforehand and the questions posed, provided a safe setting in which to explore their views about their child. This was reiterated by nursery staff participants:

'I feel really comfortable doing it, it didn't feel like it was an interview. I just felt like I was chatting with you' (Tricia, Olivia's keyworker).

However, several of the nursery staff indicated that there were other factors that may have prevented them from speaking as openly as they could have done. One nursery keyworker (Tricia) reported that she was worried that she was getting the answers right. This suggests that she was more influenced by my role as an educational psychologist than as a researcher and felt that she was perhaps being quizzed about her knowledge. Another keyworker, Una, pointed out that she had answered some of the questions in the company of her line manager. Again, this implies that she may have felt under pressure to produce responses that were considered 'correct' rather than being reflective of her true thoughts and feelings.

The emotional and affective factors associated with having a child whose development from what is considered to be the norm are further explored in the main themes highlighted below**.**

3.3 Introduction to Analysis of Main Themes

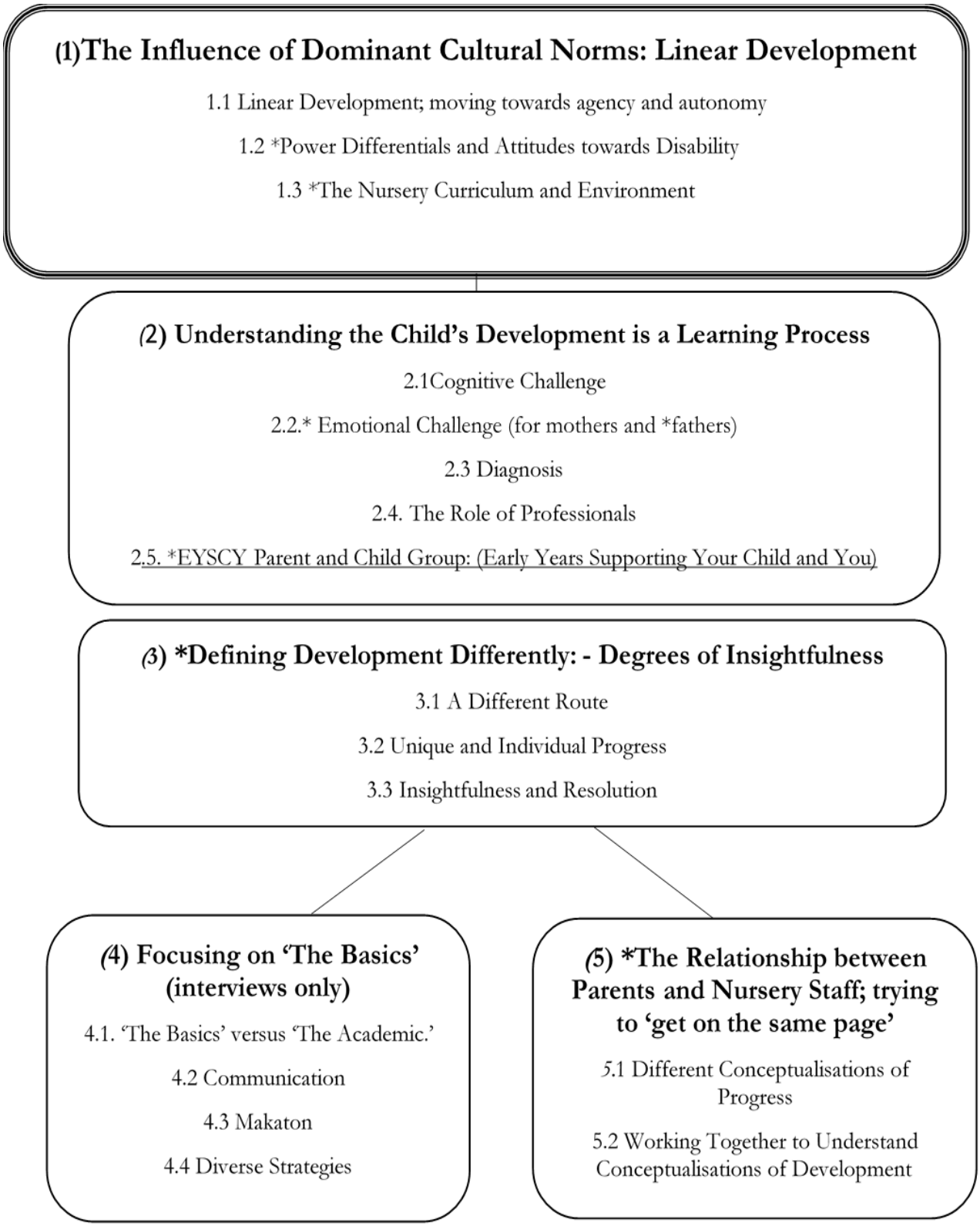
Five over-arching themes emerged from the analysis; one of which is considered as an overarching 'umbrella' theme since it highlights the influence of dominant cultural norms and ensuing power differentials on participants' conceptualisations of development. This is prevalent throughout interviews with both parents and nursery staff. The other main themes that emerge include participants' conceptualisations of development as a learning process; how their conceptualisations may have changed; what they believe is an important focus for their child's learning, and what they believe helps or hinders the child to make progress. The aim of the qualitative analysis is also to highlight distinct similarities and differences between the two groups (parents and nursery staff) and to point to particularities in how individuals understand their child's development based on the child's presentation and cultural influences.

Under the title of each theme, a table summarises the number of examples of each of the subthemes elicited from the interview data and the number of sources from which they were extracted. This enables further comparison of parents' and nursery staff responses. The information included in each of the tables is extracted from four or more sources from each of the participant groups (parents and nursery staff). Examples are also included from a smaller number of sources if the information highlights a significant discrepancy or comparison between the two groups or indeed between individuals.

The table is followed by more in-depth analysis of the interview data. Pertinent information from the two focus groups – for example, information which confirms a theme, augments it or which denotes a new subtheme, is embedded within the analysis of the qualitative data.

Diagram 2. Themes and Subthemes from Interviews and Focus Groups

(Subthemes expanded upon in the focus group are highlighted with an *. The extra subtheme which emerges from the focus group data is highlighted with an * and underlined).



The themes remain the same for the focus group since these themes form the basis of the discussion yet those highlighted with an asterisk indicate a new subtheme or a subtheme which is augmented as a result of the focus group discussion. Indeed, in the context of a group and when both parents and nursery staff were present, the significance of a number of the subthemes became more pronounced; in this collaborative setting, there was more focus on relationships between parents, nursery staff and professionals, and on attempts to adopt a collaborative approach to promoting their child's progress. Consequently, there were more responses which related to theme 5, 'The Relationship between Parents and Nursery Staff', and to Theme 1; subtheme 1.2: 'Power Differentials and Attitudes towards Disability', and subtheme 1.3: 'The Nursery Curriculum and Environment.' Repeated references to the EYSCY group meant that this merited its own subtheme: 2.5. 'EYSCY Parent and Child group: Early Years Supporting Your Child and You.'

The supportive presence of other parents in the focus group perhaps explains why parent participants discussed the emotional impact of trying to understand their child's progress more openly than they did in the individual interviews. There was thus further elaboration of the subtheme: 'The Emotional Challenge.' There was also elaboration on the role of fathers, after the participants had been questioned on the child's father's role in promoting a child's progress. This had been referenced briefly in the interviews and I deemed that it merited further discussion within the context of the group discussion. Theme 3, 'Defining Development Differently', was also further explored and marked a shift in the thinking of the parents since the time of the initial interviews; in the focus groups, more repeated references were made to the individual nature of the child's progress than to typical linear conceptualisations of development.

Each of the themes is presented and analysed in the same manner: the theme is introduced in a table which contains the subthemes and the number of references made to each of these. The number of sources (i.e. the number of participants) from which the references have been extracted is also included. Further analysis of this data is then included in a broad summary of the theme in question. This is then followed by a more in-depth qualitative analysis of each subtheme which includes relevant quotes from individual participants.

3.3.1 Theme 1. The Influence of Dominant Cultural Norms: Linear Trajectory

The table below details the number of references pertinent to each subtheme made by the participants (referred to in the table as 'sources.') These are further explored in the summary provided below.

Table 7. Number of Interview Sources and References for Subthemes in Theme 1.

	PARENTS		NURSERY STAFF	
NODE	**Number of Sources**	**References**	**Number of Sources**	**References**
1.1.VOCABULARY OF LINEAR DEVELOPMENT	9	38	6	27
1.2.POWER DIFFERENTIALS AND ATTITUDES TOWARDS DISABILITY	8	68	4	8
1.3 THE NURSERY ENVIRONMENT AND CURRICULUM	7	22	8	48

3.3.2 Summary of Analysis of Theme 1

A summary of the analysis of Theme 1 is provided below, followed by more in-depth analysis of each of the subthemes.

A key aim of the research was to explore the influence of current cultural norms and models of disability on conceptualisations of development for young children with complex additional support needs and to ascertain the extent to which the views of nursery staff and parents' views conflict and converge. Responses indicated that although parents and nursery staff participants interact with competing models of disability (medical and social), their initial understanding of a child's progress is based far more on perceived 'norms' of child development. Thus, it is not prevalent models of disability which primarily inform how the progress of a child with complex additional support needs is perceived but instead, notions of typical development permeate language and understandings and therefore influence these models.

Underpinning participants' responses are implicit references to influential theories of development (e.g. Piaget, 1964) and cultural expectations which assume that development consists of a sequence of stages through which children proceed. This is the dominant discourse to which parent participants return throughout the interviews. This is particularly true for parents, eight of whom refer to negative attitudes towards disability which emphasise within-child 'impairment' and the extent to which their child differs from perceived norms. This recognition of difference establishes a power differential and the reduced status of both mothers and their child. Whilst all parent participants use the language of linear development, six of the nine nursery staff do too. Indeed, it appears that there is no other means of establishing a baseline of a child's competencies. These 'norms' attach importance to a child's sense of agency and to their increasing autonomy and independence. They are also reinforced by the language of progress, described metaphorically in everyday language as moving forwards and in education as '*reaching a goal'* or *'as a staircase which pupils ascend*,' (Didau, in Wallace and Kirkman, p48, 2017).

Although, in theory, the policy of inclusion, exemplified by the Curriculum for Excellence (Scottish Government, 2009) marks a move away from the medical model, attempts to introduce similar experiences for all children is described by nursery staff as failing to take into consideration the learning needs of children whose progress deviates significantly from what is perceived to be a typical pathway. Again, cultural understandings of progress consistently reinforce norms and fail to accept difference. Participants demonstrate an awareness of this 'poorness of fit' between a child's development and nursery activities, and the extent to which the nursery environment fails to meet their child's needs. Ironically, these are practices which may be borne out of an attempt to adhere the social model of disability to practice and to promote inclusion. This highlights the difficulty not only of moving away from dominant discourses, but also of constructing new ones. While seven parents highlight the unsuitability of the nursery environment, all nursery staff make forty-eight references to the curriculum and environment and the extent to which it can impede the children's progress, rather than promote it.

'Linear development' thus provides the starting point for people's conceptualisations of the development of children with complex additional support needs. It also shapes mothers' feelings and responses to their child, when he or she does do not adhere to the norm. Indeed, the repeated reference to and comparison with what are perceived to be norms of development, and the extent to which the children being described differ from this, results in continual conflict for both parents and nursery staff and in contradictory conceptualisations of progress. This tension is present in participants' accounts and emerges in each of the main themes. It is also evident in parents'

accounts of their sometimes difficult and emotive interactions with professionals. It is worth noting that views of other professionals mentioned have not been sought. The data is thus understood and analysed with an understanding of the highly emotive nature of the content.

Because of its pervasiveness, the theme 'The Influence of Dominant Cultural Norms: Linear Development' can be regarded as a standalone 'overarching' main theme. Since is interwoven within each of the other main themes, it is also regarded as a special subtheme of each. Examples of this theme are highlighted below in a further analysis of the subthemes. These are returned to and explored in further depth as part of the analysis of the other main themes.

3.4 Analysis of Theme 1 Subthemes

3.4.1 Theme 1.1 Linear Development; moving towards agency and autonomy

When describing the development of a child with complex additional support needs, the reference to a linear trajectory and to associated chronological norms permeate participants' accounts. All nine parent participants refer to what are considered to be typical stages of development as a means of establishing a baseline and providing a comparator. Examples include phrases such as *'toddler stage'; 'the next stage, developmentally.'*

Fiona is constantly compelled to compare her son's progress to that of his peers:

'Well we had a play date with his friend not long ago and his mother was saying he can count to 20, he can do his colours, and you're a bit like; he's (Tom's) obviously not at that stage.' (Fiona, Tom's mother).

Ruby's parents, Pam and Craig, who are in one sense cognisant of the severity of her difficulties related to her diagnosis of Rett syndrome, find it very difficult to conceptualise her progress as being distinct from what is considered to be a normal trajectory of development:

'When she was born we were resigned to the fact she was severely brain damaged anyhow and you know we would be sitting here saying; 'yea she's severely brain damaged and she could be understanding everything we're saying about her, I mean, we just don't know." (Pam, Ruby's mother)

'I just can't see any difference in her… I just don't think she's developing but I don't know, what can you do? She can't use her hands or sing.' (Craig, Ruby's father).

'It must be hard for Ruby as well if she's thinking something and can't communicate with us... she's showing you she's trying to communicate so she gets upset- she tries to get a word out, but nothing comes out.' (Craig, Ruby's father).

The quotes above suggest that Pam and Craig fluctuate between describing Ruby as either not developing at all or in fact understanding everything that they are saying – there is no middle ground.

The parents' accounts indicate that discourses of 'normalcy' influence professionals. (This will be explored further in subtheme 2.4). Assuming a typical trajectory of development is reinforced by some professionals during the assessment process, even when Ruby's difficulties have been established. Pam recounts how her health visitor informed her that she will be conducting a six-month developmental check – despite Ruby's complex additional support needs and diagnosis of Rett syndrome.

'I got a phone call in June to say she's due a 6-month assessment. I went: 'What assessment? She goes to her specialist. I don't understand what you need to see her for.' She said, 'but I really need to see her to do this assessment' (Pam, Ruby's mother).

According to Pam, this is a '*tick box exercise'* – an assessment that takes place routinely at regular points throughout a child's infancy and early childhood. Yet for Ruby, this will only serve to reinforce her difficulties and the extent to which she is not meeting typical developmental milestones.

Six of the participating nursery staff make frequent reference to the 'stages' or 'steps' which typically developing children pass through for different aspects of development (e.g. communication, physical skills) and link these to chronological norms. These often provide a baseline and a means of gauging the progress of a child with complex additional support needs – or they serve to highlight how their progress differs from the norm.

For some nursery staff, cultural assumptions and stages of development inform analyses of those behaviours which are deemed to be challenging. Even when they can describe the identified reason for the behaviour, or what the behaviour may be communicating, three of the staff still find it difficult to understand the behaviours within the context of the child's learning disabilities. They often assume the agency or intent of the child, yet often without a thorough assessment of the child's needs having been undertaken.

'Because there are a few behavioural issues as well with her, alongside the Down's syndrome.' (Margaret, Emily's keyworker).

The quote above highlights the fact that Margaret views behaviour separately from Emily's development, rather than integral to Emily's development and communication. Interventions that

are described to address behaviours do not always focus on developing the child's means of communication but are instead consistent with current accepted ways of addressing the behaviours of typically developing children of the same age. Mary, Tom's key worker, explains that they tried the bottom step at nursery as a time out for Tom, the preschool child with Cornelia de Lange syndrome.

'A time-out kind of thing, we were using and it was just on the bottom step in the hall. We were putting him on but he would just get up and run away and stuff, but then other times he was asking to get on it when he hadn't been doing like anything Sometimes Fiona was saying that he would find it quite funny to get on it and other times he was laughing about it and then other times he was totally distraught about it so it was just trying to.. his kind of understanding of it as well, I think wasn't quite clear.' (*Mary, Tom's keyworker*).

Here, Mary demonstrates her awareness of the fact that Tom did not understand the purpose of the step. The fact that she uses the past tense when describing it suggests that they no longer use it, yet it was still a strategy they felt they could try, perhaps because it is used commonly as a means of 'disciplining' typically developing children. Was it employed because they have little knowledge or understanding of Tom's comprehension levels, or rather, because they lacked other strategies to address what were deemed to be more challenging behaviours?

Ainsley and Una refer to the difficulty they have interpreting Daisy's behaviours in relation to her learning difficulties or because of her volition.

'*There's a lot of stubbornness in there as well where you're kind of thinking is it understanding or is it not.' (Una, previous keyworker of Daisy).*

'Yea, pretty much it is a lot of that where you're putting it down as an ASN and actually it's just 'I'm just not doing that.' (Una, previous keyworker of Daisy).

They refer to her behaviour as '*toddler behaviour*', thus ascribing perceived cultural norms and expectations of how children will behave at a certain stage.

The tendency to ascribe agency to some behaviours (i.e. a child deliberately choosing to act this way) is linked to what Landsman (2005) describes as western 'individualistic' notions of 'personhood' which include and value notions of agency and autonomy. This perhaps also explains why there is often a propensity amongst some mothers and professionals who are trying to understand their child's learning to describe some of their barriers to learning in terms of personality traits - and thus ascribing agency to their behaviours - rather than in terms of a

difference in how they learn. Una describes Daisy as '*stubborn'*. Similarly, Sylvie twice refers to her daughter being '*very very headstrong'* and twice to her being '*very determined.'*

'It's hard to tell whether it's down to an actual problem ...or a personal 'I don't really feel like doing this right now.'(Sylvie, Daisy's mother).

As the quote above demonstrates, on several occasions throughout the interview, Sylvie explains finding it difficult to understand which aspects of her daughter's development can be considered consistent with typical development and which aspects are attributable to her learning difficulties. In particular, parents and nursery staff find it difficult to determine whether more rigid behaviours are consistent with a child's difficulties or with toddler behaviour. However, it may be that in some instances, the use of personality traits or adjectives serve to minimise difficulties and normalise behaviours to fit with what is perceived to be a normal trajectory of development.

The vocabulary of linear development resonates with all the participants in the focus groups when it is presented to theme from the individual interviews:

'Even from when I was young, as I say, from the minute they're born, you've got this line and this line follows them until they get to uni…to jobs…the whole of society does it.'(Hannah, Emily's mother).

'The information you get for Ava (Emily's older sister) and the information you get for Emily, it's the same and it shouldn't be the same. From birth, it's different. So, it's constantly this line and you think; "Oh, she's gone below it, oh, she's gone above it." Nobody actually explains; "Oh, it's okay (not to follow it)". (Hannah, mother of Emily).

In the quotes above, Hannah describes the linear trajectory as being culturally pervasive from birth. Although she now recognises that her own child does not follow the same trajectory as that of her other daughter, she emphasises that this was not explained to her when Emily was born.

One of the nursery staff, Una, refers to her own personal experience as a mother:

'Life doesn't follow a path for anyone. So, he (my son) got to twenty-two, he can ride a bike.. but next year he might not be able to. You just don't know what's around the corner.' (Una, Daisy's keyworker)

Here she refers to her own adult son's experience of illness which resulted on him no longer following this line. As a result, Una rejects this linear trajectory all together – indicating that for everyone, development and progress cannot be perceived as a set of predetermined steps at any time of life. Instead, the reality is much messier and much less predictable. Una challenges deeply ingrained assumptions that progress and development will follow a predetermined path, indicating the constraints of the dominant discourse and indeed the negative impact that this discourse can

have. Yet distancing ourselves from dominant discourses is not an easy or quick or even complete solution (Romme, Escher, Dillon et al., 2009). This will be further explored in the Conclusion.

3.4.2 Theme 1.2 Power Differentials and Attitudes Towards Disability

Such is the pervasiveness of a linear trajectory of development that it is inextricably linked to 'power.' David Smail defines power as 'the means of obtaining security and advantage' (Smail 2005, p.28) which operates primarily through social structures and institutions – e.g. through education and social and family relations. In the context of this study, cultural linear narratives of progress are closely linked to cognitive capabilities and other attributes which are highly valued in current society, such as physical strength, agency, and voice. Indeed, a child's ability to make choices and to play an active role in their lives is consistent with autonomy, so valued in individualistic western societies (Tamis- LeMonda, Way, Hughes, Yoshikawa, Kalman, & Niwa, 2008). This reinforces pervasive negative beliefs about children for whom autonomy is an unachievable goal.

According to Landsman (2005), a sense of agency is not only tied up with notions of linear process, but with a focus on the future. It is thus inextricably linked with the concept of hope (Becker, 1997). The impact of this is twofold; it encourages parents to continue to focus on the development of such skills in their child, (indeed, five of the nine parents continue to emphasise a focus on verbal skills, when their child's means of communication is very different); it also significantly influences their own feelings as a mother. Landsman (2005) refers to the 'diminished motherhood' felt by mothers whose children fail to develop the skills that are highly valued. Thus, for parents, too, the birth of a child with complex additional support needs results in a fundamental loss of power and control.

The parents in the study recount their own initial loss of control and ensuing difficult journey in understanding their child's development and parenting a child whose progress is not what is expected. Parents' accounts thus demonstrate a tension between the cultural pressure for their children to reach typical milestones whilst at the same time being aware of the stark difference between their child's development and that of other children. This results in parental anguish when describing their child's development to others. Becker (1997) highlights the effort to create a sense of continuity after such a disruption which encourages parents to continue to adhere to typical models of development, as a means of regaining power and control over their lives. In the early stages of a child's life, this is reinforced by the avoidance of family and friends to discuss the child's development in different terms.

Jennifer, mother of Joe, describes the reactions of her family who minimise concerns and attempt to 'normalise' aspects of Joe's development.

'A lot of the family are like 'oh he's fine, there's nothing wrong with him' I just get to the point now; I'm just, I don't even try to explain to them. I'm like: 'you've got his diagnosis, we know.' (Jennifer, Joe's mother).

Jennifer indicates that family members are quick to dismiss his differences – perhaps because they do not want to see them, do not understand them, or it is easier to ignore them and pretend that he is progressing 'normally', even though he now has a recognised label which highlights 'difference.' This is reinforced by the fact that Joe's physical presentation masks his diagnosis.

'*He doesn't have a sticker on him or a badge to say and he looks the same as everybody else.' (Jennifer, mother of Joe.)*

This has led to Jennifer having to having to 'put on a shield' when facing comments from others. This is explored further in Theme 2.2.

'But see now, I'm just like 'let people look; let people make comments' because you can't challenge every single person who's going to make a comment about your child.' (Jennifer, mother of Joe.)

The quotes also emphasise mothers' own feelings of inadequacy around their child's progress:

'*She still erm doesn't talk in sentences and so on which is not overly concerning for the most part as far as delays and milestones go except that we're from a kind of family where everything was quite early and quite well established.' (Sylvie, Daisy's mother).*

Here, Sylvie highlights the increased difficulty of viewing her daughter's 'delay' in reaching milestones, within the context of her high achieving family. This demonstrates that cultural notions of progress are intertwined with beliefs about what constitutes being a successful mother. In a culture where a child's attainment is often attributed to the success of the mother and where reaching milestones is often viewed as something of a competition (Carey, 2014), a child's atypical progress or lack of perceived agency can be a source of guilt and even shame. The socially constructed 'reduced personhood' of a child with a disability is linked to a woman's experience of diminished motherhood (Landsman, 2005). Indeed, the mothers' accounts indicate their feelings of disempowerment and lack of control over their child's progress.

In the early months of her daughter's life, Lucy, who is very well supported by family and friends, recalls being reluctant to inform those outside of her close circle of her child's disabilities.

'I've just really gone kind of public as you say, with this. Obviously close family members and our friends know but kind of out with it, no, they didn't.' (Lucy, Maddie's mother).

The sense that she must hide her child's development to others indicates the pervasiveness of typical notions of development and the lack of knowledge, recognition and even acceptance of difference. More significantly, it indicates her sense of shame as a mother.

All participating parents have experience of professionals who have failed to highlight how their child's development is not consistent with what would be expected for a child of that age. It is probable that the dominance of cultural norms, and continuing pejorative notions of disability, mean that parents, families and indeed some professionals cannot process nor comprehend a child's development as being significantly different from the norm. For parents who may have highlighted these 'differences' and who are seeking further information, this lack of validation or acceptance is described as very disempowering.

For Lesley-Anne, the fact that some professionals normalise her daughter's behaviours results in her repeatedly doubting her own concerns. This contributes to what she describes as an obsessive seeking out of information

'I'd watched every video on YouTube of autistic kids, because, at the beginning I thought 'I'm going nuts.' People are saying to me 'oh this is just like development and this and that' and I think, no this isn't, this is autism and I'm so consumed by it.' (Lesley-Anne, Leah's mother).

Lesley-Anne's attempts to highlight her daughter's difficulties are described as being repeatedly dismissed- to the extent that she questions her own thinking. ('*I'm going nuts.*') This failure of others to take on board her understanding of her daughter contributes to her feelings of 'diminished motherhood' and also reinforces the existence of professional and interpersonal power. Although research into parents of older children with disabilities suggests that the experience they have had has made them experts, (de Geeter, Poppes & Vlaskamp, 2002), this is not the case in the early years and parents must acquire the relevant information about the nature and course of their child's learning difficulties or disorder.

All parents in this study highlight their quest for knowledge and their reliance on other multiagency professionals (e.g. speech and language, occupational theory, educational psychology) for ways in which they should understand and promote their child's progress. Nursery staff too, recount their need for support from other professionals. These professionals possess knowledge that they are lacking; the parents and nursery staff are dependent upon them to impart this and sometimes to give their child a diagnosis. This positions the professionals as the 'experts' in understanding a

child's development, thus establishing a power differential between them and parents and nursery staff. Three of the mothers whose children's difficulties become more apparent with time (Jackie, Lesley-Anne and Jennifer, all of whom have a child with autism), report that their concerns are minimised when they first attempt to discuss it with other professionals.

'I can remember going to the GP the first that I went, and she says to me 'oh, she's not got monotone babbling, she's fine.' (Lesley-Anne, Leah's mother).

In the quote above, the doctor normalises Leah's development and is dismissive of Lesley-Anne's concerns about her daughter's communication. The parental accounts suggest that some professionals may at first veer towards a linear trajectory and presume typical development when a parent first articulates their concerns - consequently minimising difference and making parents feel that their concerns are not being validated. Even when a child has significant difficulties which have been apparent from birth, some participating mothers report professionals' misunderstanding of their child's development. The most striking example of this is recounted by Pam, Ruby's mother. Prior to Ruby's diagnosis of Rett syndrome, Pam reports that her concerns are normalised and indeed dismissed when she discusses these with a health visitor, despite the fact that Ruby was resuscitated for a long period of time at birth:

'So, then I went back again to the health visitor to say that 'I can't believe you're not taking me seriously. There's something wrong', and then I got told she was lazy, and she shouldn't be on a bottle and then I went: 'but I can't get her to drink from anything else - she just wasn't able to swallow -she could suck out a baby's bottle but not a beaker.' She said 'you need to get her moving her hands. Are you playing with her?" (Pam, Ruby's mother).

Pam describes the health visitor as interpreting all her concerns in accordance with a linear trajectory of development and in doing so, negatively judging her parenting. It is important to note that Pam's own personal interpretation of this interaction is presented and that the health visitor's views were not sought. However, the accounts highlight how disempowered parents can feel, when attempting to highlight concerns that their child's development is not typical. In such instances, parents lack knowledge and are reliant on professionals (regarded as perceived experts) to provide them with more information about their child's progress. Yet some professionals are depicted as continuing to use the linear trajectory of development as a realistic gauge of the progress of a child with complex additional support needs. (The role of professionals is detailed more fully in Subtheme 2.4).

Interestingly, as is detailed in Theme 2.4, two of the parents report that they value direct input from professionals (more than they do advice about how they can promote their child's skills) – indicating that they believe that this will have more of a positive impact on the child's progress.

'*Occupational therapy, speech and language therapy input is ad hoc, it is very much ad hoc; they're like: "Oh she's doing quite well, I'll leave it six months before I come back out and see her. I tick a box to say that I still come out and see her, so I'll see her." Erm..not all of that time, that sounds very bitter, its not all of the time, its not always like that, there's things that the speech and language therapist is working with me on about suggestions, other types of communication strategies and so on to see if they're more appropriate or see if we can move things along because she is doing quite well with the Makaton and so on but at the same time, its all been done on a very informal basis.' (Sylvie, Daisy's mum).*

Here, although Sylvie acknowledges the collaborative working with the speech and language therapist on communication strategies to support Daisy, she also portrays her disappointment at the lack of frequent and direct involvement from professionals who are supporting Daisy's development. Yet this emphasis on direct involvement may inadvertently exacerbate the existing power differential by reinforcing the belief that an understanding of the child's progress lies outwith the norms of how progress is understood, and thus within the specialist domain of the very few. Jackie describes what she had thought this professional input would involve:

'*If I had thought before I had kids like I would end up having a child that was non-verbal or anything like that I thought that they would get all these people doing things one on one and stuff like this, you know like they do in America and in the movies.' (Jackie, mother of Olivia).*

Despite her initial idea of what she had thought professional involvement would entail, Jackie indicates - albeit reluctantly – that she understands that the role of the professionals is to impart their knowledge and to build the capacity of parents.

'It's just that advice that they give you... It is a , I mean especially with Olivia, she's under 5, so a lot of the progress she's got to make, it has to be me that does the work for it.. so as long as you're putting the work in and especially if you've got people backing you up in nursery doing the same things .' (Jackie, Olivia's mother).

The quote above highlights that the involvement from professionals has built her capacity to support Olivia and in doing so, minimises the power imbalance between herself and those supporting Olivia. She is the one who 'does the work' with the professionals 'backing her up.'

Interestingly, Jackie, who possesses a very equal relationship with the nursery worker who supports her daughter, describes a two-way sharing of ideas and strategies and no power differential. This

differs from the account of several of the parents who make reference to the fact that their opportunity to talk about their child's development is either very limited (Sylvie, Daisy's mum) or only offered in a review meeting context(Lesley-Anne, Leah's mother) where already established targets are presented to her. Such processes can in fact serve to reinforce the unwritten rules in educational practice which maintain power differentials between parents and professionals.

Conversely Jackie's account indicates that she informs what nursery have put in place to support Olivia's progress:

'It's great that nursery has mirrored what I've been doing.. that has made such a big difference for Olivia. (Jackie, Olivia's mother).

This is reiterated by Olivia's keyworker, Tricia, who describes a '50-50' relationship:

Like you're working on something at home, you tell us, ..we're working on something …like its a partnership' (Tricia, Olivia's keyworker).

Although Jackie articulates her gratitude towards Olivia's key worker, she also demonstrates a conviction that her role as Olivia's mother enables her to take the lead in terms of suggesting what should be a focus for her progress. Her account suggests that not all mothers faced with parenting a child who does not demonstrate the skills typically valued in society feel a sense of 'diminished motherhood' (Landsman, 2005). Whilst it is evident that her very positive and equal relationship with the nursery has contributed to her strong sense of ownership of her daughter's development, her previous experiences with her son has also served to equip her with knowledge that the other participating mothers must seek out (Theme 2.1) This further minimises the power differential.

In this study, an equal partnership between home and nursery described is not evident in all participants' accounts. As detailed in theme 5, five of the parents report differences in opinions about their child's progress of which nursery staff are unaware. Sousa (2015), highlights the unwritten rules in education which prevent parents from expressing their feelings openly for fear of being judged. When a child has a disability, the unequal power relationship may be reinforced. Indeed, Lalvani's qualitative research highlights the extent to which parents are pathologised (Lalvani, 2015). There has been no research into the emotional labour demonstrated by both mothers and fathers when discussing the needs of their child with complex additional support needs, yet the studies above suggest that parents may often feel unable to articulate their feelings about their child's development within the nursery setting.

3.4.3. Theme 1.3. The Curriculum and Nursery Environment

Although the nursery staff participants report that they have invested time in learning about a child's individual needs, participants' accounts indicate a frequent mismatch between the curriculum, the environment and the learning needs of the child. In the interviews, parents and nursery staff indicate that nurseries, in terms of their size, number of people and learning activities, have not been adapted to best promote the progress of children with complex additional support needs. This is the case for two parents choosing to move their child to an ASN nursery, where the number of children is significantly smaller and where there is a higher staff-child ratio.

The following quotes highlight parents' and nursery staff recognition of how different aspects of the environment pose a barrier to learning. The nursery environment, therefore, places children with complex additional support needs at a disadvantage

'I think if she was in a quieter environment erm with less stimulation going on and erm.. (it would be) kind of much more suited coz she likes the 2-3 room; she still likes to go through there.' (Tricia, Olivia's keyworker).

'They found that it wasn't just who else was in the room:-she was quite happy with who was there, but she couldn't cope with the room itself; it was too wide, open, too different, too many things - she was completely overwhelmed, over stimulated and quite often ended up having really bad days behaviourally wise.' (Sylvie, Daisy's mother – referring to the mainstream nursery class within a primary school).

In this quote, Sylvie emphasises that even during the school holidays when the number of other children is substantially less, Daisy is still negatively affected by the environment and by the layout of the room itself.

In the interviews, participants also refer to the nursey tracking tool which continues to be employed by nurseries as a means of (unsuccessfully) attempting to track these children's progress in accordance with typical milestones. Although the nursery staff participants have all had experience of supporting children with complex additional support needs, they refer to other nursery staff who have had no knowledge of working with children with this level of need and who continue to adhere to norms of development and mainstream practice.

'They just didn't know where to begin and they didn't know kind of what they should be doing for the children…'we should be doing the curriculum, and we should be doing these things', and we can't with these children, they're not at that stage yet.'(Tricia, Olivia's keyworker).

Interestingly, the curriculum to which Tricia refers is that which has been developed and created to encompass the needs of all children from the ages of three to fourteen. Yet, by adhering to the

Curriculum for Excellence, Tricia implies that staff new to this sector demonstrate a lack of knowledge about the children's needs. The repeated use of the word 'should' implies that these nursery staff feel obligated to implement the curriculum, suggesting that it is imposed rather than implemented in accordance with an individual child's need. This indicates, too, how the power of the linear trajectory is maintained and reinforced through the curriculum. The use of the word 'yet' also indicates that there is an implicit understanding that a child may reach a stage, albeit it at a different pace and that there continues to be a focus on development towards a specific destination.

'When you've got a big group in a big playroom, and you've got free play to manage we well, like I'm all for inclusion in the big nurseries, I think provisions are too big and you can't I mean we're sitting at an 80/80 ratio.' (Vicki, keyworker of Joe- who works in a large, local authority standalone nursery).

Vicki's account above suggests that whilst she believes in inclusion in principle, the environment within nurseries has not been sufficiently adapted to ensure that children with significant learning difficulties can access learning.

Interestingly, this subtheme is corroborated by participants in both focus groups and is elaborated upon within the group setting. Much of the discussion centres on the inappropriateness of the nursery environment setting and how this can pose a barrier to the learning of young children with complex additional support needs. Consistent with both the social model of disability and cultural historical model, there is an agreement amongst participants that progress is impeded when the child cannot engage in their environment and in learning activities. Evident in the analysis of focus group data, is the consensus amongst both parents and nursery participants that nursery staff consider themselves to be contravening what is expected of them by adapting the environment and curriculum to meet an individual child's needs.

'It's a shame you can't keep them in that room: that's the sad thing.' (Pauline, Maddie's keyworker).

'Not feeling as though you're breaking the rules and being relaxed about it.' (Tricia, Olivia's keyworker).

'Daisy was due to move on (to the room for older children) but she didn't move up – she stayed with us because that was the stage she was at.' (Una, Daisy's keyworker).

'According to the way it was supposed to go, she was supposed to go up. But if she had gone up, she would have moved backwards rather than forwards.' (Hannah, Emily's mother).

The quotes above highlight the participants' strong sense of being bound by culturally enforced norms such as transitioning children to a different room in nursery when they reach the age of

three. Phrases such as: *'You can't keep them'*; (Pauline); '*Breaking the rules';* (Tricia) and '*she was supposed to go up'* (Una) emphasise the influence of these norms and the extent to which both staff and parents feel that to contravene these rules is unacceptable. Indeed, Michelle reiterates how grateful she is to nursery staff, thus implying that what they have done has gone above and beyond common expectations of how nursery staff are expected to meet children's needs.

This participants' accounts suggest that, despite more recent changes to the curriculum for this group of learners, (Education Scotland, 2019), notions of inclusion are still primarily ideological – denoting a human rights perspective and the presumption that children should access the same activities and environment that have been developed for their typically developing peers. In this sense, the terms inclusion is used interchangeably with mainstream since the presumption here is that all children should access the same learning experiences. The accounts indicate that the idea of inclusion is afforded more weight than the reality of the lived experiences of young children with complex additional support needs accessing a busy mainstream environment. What is still lacking at a curriculum level, is a broader acceptance and indeed acknowledgement of difference and an in-depth consideration of ways in which the development of an individual child can be better understood, articulated and embedded within educational practice.

3.5 Theme 2: Understanding the Child's Development is a Learning Process

The table below details the number of references pertinent to each subtheme made by the participants (referred to in the table as 'sources.') These are further explored in the summary provided below and followed by a more detailed analysis of each subtheme.

Table 8. Number of Interview Sources and References for Subthemes in Theme 2.

	PARENTS		NURSERY STAFF	
SUBTHEME	**Number of Sources**	**References**	**Number of Sources**	**References**
2.1. COGNITIVE CHALLENGE	9	34	8	52
2.2 EMOTIONAL CHALLENGE	9	88	3	18
2.3 DIAGNOSIS	8	29	6	10
2.4. THE ROLE OF PROFESSIONALS	9	105	8	61
2.5 EYSCY	4	26	2	4

3.5.1 Summary of Analysis of Theme 2

Cultural assumptions of a linear trajectory of development and the value that is attributed to it make it difficult for participants to make sense of a child's progress when it does not adhere to these norms. This is especially evident from the participants' accounts when a child's learning needs are more significant or profound and deviate more from an assumed trajectory of development. All participants describe the *learning process* in which they engage to comprehend the child's development. Apart from Jackie, whose older son has autistic traits, parents all start off from a position of no or very little knowledge and indicate that learning about their child's development has challenged them cognitively. Similarly, all nursery staff explain that they did not arrive in the job with a knowledge of how children with this level of need may progress. Whilst parent participants make thirty-four references to this cognitive challenge, this is superseded by nursery participants who make fifty-two. Yet parents also face the ongoing emotional challenge of supporting a child whose development does not adhere to cultural recognised norms. The significance of this subtheme is reflected in the frequency with which it is extracted from the interviews of all parent participants; there are eighty-eight examples of this, in comparison to

eighteen examples noted by only three of the nursery staff. This theme is discussed more openly and in greater depth within the context of the focus groups. In this group setting, further emphasis is placed on the need for nursery workers to have compassion in order to address the learning needs of children.

For eight of the parents, the interviews indicate that a child's diagnosis can help to clarify aspects of their child's development, in addition to providing further information for three of the nursery staff professionals. This can be beneficial if, as the accounts suggest, nursery staff use knowledge of specific aetiologies in conjunction with an assessment of the child's individual needs, rather than relying on stereotypes of how a child with a specific diagnosis may progress. The diagnosis process is intertwined with interaction with and involvement from a range of multi-agency professionals. Whilst five of the nursery staff refer to the importance of this input in terms of increasing their own knowledge and providing them with support in order to better meet the child's learning needs, parents' engagement with professionals is described as far more complex. All nine parents make one hundred and five references to liaising with these professionals. Without recourse to dominant cultural norms of child development and parenting practices, they are reliant on them for information. This adds a power differential – explored in the overarching theme 1.2 - which can lead to difficult relationships, at times, and to parents reporting feeling a lack of control or ownership about the child and his or her needs and diagnosis.

3.6 Analysis of Theme 2 Subthemes

3.6.1 Theme 2.1 Cognitive Challenge

Staff and parents emphasise the importance of their own role and their determination in making sense of and supporting the child. This is just as evident in the accounts of parents who received a diagnosis of their child's disability at birth. This quest for knowledge highlights perhaps the importance of parents actively engaging in this process as a way of getting to know and understand their child. It also represents a way of attempting to take control when they feel disempowered and are obligated to seek out information about their child's development from professionals. Similarly, even when nursery staff have previously worked with children with complex additional support needs, they still emphasise their drive to understand more about the development of the child with whom they are currently working. This suggests that it is also important for staff to get to know and understand the child in order to then address their learning needs.

All nursery staff participants have actively sought other means of learning more about the child's development and progress:

'I'm the type of person if I get training then I'll go home and read about it for three weeks' (Pauline, Maddie's keyworker)

'So, I've spent a lot of time kind of researching – like in my own time – personal research – on the computer - streaming into live videos with psychologists from America – just kind of reading up on the national autistic society.' (Vicki, Joe's keyworker).

'I did some research myself just online so that I knew what it was and trying to understand it.' (Mary, Tom's keyworker).

These three quotes demonstrate this quest to obtain more information and a wish to acquire knowledge as a means of understanding the child's development and his or her progress. It is perhaps the case that those staff who best address the needs of children with complex additional support needs are those who actively seek out more information. Indeed, all eight keyworker participants highlight the importance of getting to know the child and spending time observing them in the nursery environment.

'I just try and put myself in Joe's shoes and think how would I feel if this was me?' (Vicki, Joe's keyworker)

Here, Vicki describes her attempt to understand Joe from his perspective. This highlights the individual nature of his development and the importance of obtaining an in-depth understanding of his needs.

Nursery staff participants also indicate that much of what they have learned about a child has been 'on the job':

'It's just experience and things like that.' (Lizzie, Ruby's keyworker).

'And the experience you build up over the years, it's night and day from where I was before.' (Tricia, Olivia's keyworker).

The quotes above indicate that their hands-on experience has been of importance in aiding their understanding and approaches to supporting the child.

Staff indicate that their colleagues with previous experience have helped them to understand more about how to support a child's progress. In addition, all the participating nursery staff refer to training which has aided them in their understanding. For example, six of the nursery staff participants have attended training which is focused on explaining autism and the characteristics of those children with an autism spectrum disorder (ASD) diagnosis. Only three members of nursery staff have accessed more general training which provides further information about the

development of children with complex additional support needs. This has been specifically on the South Lanarkshire Framework for supporting children with complex additional support needs (referred to as 'the Framework'), developed as a result of both a local needs analysis and national priorities with the aim of supporting staff to implement the curriculum for pupils with complex additional support needs (South Lanarkshire, 2015; Appendix 2). Given that I had been involved in the initial development and implementation of The Framework, I did not pose any questions directly relating to it unless nursery staff initiated information. The two nursery staff participants who worked in the ASN nursery referred to the positive impact of both the document and the associated training on their practice.

'Through The Framework as well, reading that as well, the severe and profound, even just the definitions as well, clarifying that as well, between the differences and how to support children's behaviour' (Lizzie, keyworker at ASN nursery and for Ruby).

Here, Lizzie indicates how this document and training has increased her knowledge. Her quote reflects one of the outcomes of the initial evaluation of The Framework document (Rees, Tully and Ferguson, 2017) which indicated that The Framework had helped staff to conceptualise progress for individual pupils and had provided a clearer way of setting targets based on an assessment of a pupil's learning needs, rather than on common conceptualisations of development. In addition, Mary, who works in a private nursery but who had participated in a consultation session on The Framework with me in my role as an educational psychologist, refers to how she has used the contents of The Framework to aid her in supporting Tom. She highlights the fact that the Framework is the only recourse she has had to information about supporting children with more severe needs.

The following quote from Lizzie also indicates how useful she would find 'modelling' as a means of putting into practice new resources or activities:

'Like I learn better and take it in better myself when you're actually doing it with the children erm, so I think for me it would be maybe coming in and showing us like the different things and how they work or how you can use the different items with the children. I think that would be quite useful. Yeah... I find that much better for me, if you're actually being shown things, you remember a lot more.'(Lizzie, Ruby's keyworker).

The quote suggests perhaps that training would be more impactful if it is followed by further support and coaching. This is consistent with research from implementation science which suggests that a coaching and mentoring facilitates the application of new knowledge to practice (Blase, Fixsen, Naoom & Wallace, 2005). Mentoring that includes in-classroom coaching and out-

of-classroom consultation is emerging as a promising professional development strategy that improves the behavioural and educational outcomes of school-based interventions beyond those achieved through traditional stand-alone training sessions (Haskins & Loeb, 2007; Gorman-Smith, Beidel, Brown, Lochman, & Haaga, 2003).

Parents' accounts are imbued with a strong sense of uncertainty about their child's progress and about obtaining a clear conceptualisation of what constitutes development. Parents use the following words to highlight this: '*lack of knowledge'; 'unclear'; 'we don't get it.*' On several occasions, Craig, the father of Ruby, refers to her development as a *'mystery'*, emphasising the extent to which he feels in the dark about how she will progress. This may be particularly true for parents whose children have very complex health needs, and where there may be further regression, as is the case with girls who have Rett Syndrome:

'I mean I'm not concerned if she does recognise or not recognise … for me it's about making sure her health for me it's a priority that her sores or her chest or whatever is my priority for her that she's got the best possible life.' (Pam, Ruby's mother).

In this quote, Ruby's mother, Pam emphasises that her focus is on understanding and addressing her daughter's health needs, rather than on her development:

Lucy, mother of Maddie, refers to the: 'm*illions and millions of things going around in my head'* to describe her constant mental preoccupation with her child, Maddie, and her progress, and with her and her husband's attempts to make sense of her daughter's diagnosis. She does this using an analogy:

'I think a lot of it has come from ourselves. I think you have to understand it yourself first of all. I suppose it's like people who smoke you know, and they want to stop smoking. You need to really want ... to do it and understand so I think I had to really get my head round it.'(Lucy, Maddie's mother).

By comparing it to another difficult process, she highlights the fact that as parents, they needed to understand Maddie's diagnosis and disability in order to be able to focus on her development. Once again, she emphasises the cognitive challenge involved in '*getting her head round it."* The participating mothers recount that they are motivated to do this research.

'I've always been one of those people that will research, research, research.' (Jennifer, Joe's mother).

The mothers' personal quest for knowledge and a drive to understand more about their child's development can be interpreted as a means of reducing the uncertainty and endowing them with a sense of control. In this sense the quest may be empowering. Landsman (2005) suggests that,

because of their search, mothers lay claim to their own special form of knowledge which they use as a means of challenging the position of biomedical knowledge. In her study, mothers repeatedly describe coming to recognise and value their own expertise and argue that no one can know a child like their mother can.

Whether this specialist knowledge is the domain of mothers, rather than fathers, has not been explored in research. In this study, the only participating father indicated that he did not wish to obtain further information – yet this could be attributable to the complex and degenerative nature of his daughter's disability, rather than being reflective of his role as a father. This will be further explored in Theme 2.2. In this study, too, only one mother, Jackie, highlights the extent to which her own knowledge as a mother supersedes those of nursery staff and professionals. She does this on seven occasions.

'It's trying to get it so that everybody else can (communicate with her) coz no (t) everybody's her mother and no (t) everybody knows her the way I know her.' (Jackie, Olivia's mother).

Interestingly, this mother is the only participant with an older child with similar difficulties to those of her daughter.

'I don't think... I don't think it would have been easy, as easy for me with Olivia if it wasn't for the fact that I was so... already up to scratch with it all for Leo because Olivia is so much more like, severe, obviously, she's non-verbal it's there's more struggles there with Olivia but I think I was more prepared for Olivia because of Leo.' (Jackie, Olivia's mother).

The quote suggests that she has already developed a more in-depth understanding, because of her previous experience and the time spent seeking out information about her son's development. This has led to her increased knowledge. For her, the time invested in getting to know her older child has been a fruitful one and has paved the way for the process of understanding and getting to know her daughter. Although it could be presumed that to have two children with a disability would be more challenging emotionally, Jackie describes the learning process with her second child as being an 'easier' one.

In the focus groups, all four parent participants reflect on their increased knowledge over time:

'*I've learned so much I could write a book.' (Lucy Maddie's mother).*

'It wouldn't have taken someone too long to do a wee bit (of research) themselves.' Hannah, Emily's mother).

Interestingly, Hannah highlights that fact that she was pursuing this research alone – and that she would have preferred extra information regarding her daughter's development from infancy

onwards. This is a theme that she returns to in both the interview and focus group. Conversely, Fiona, Tom's mother, highlights the amount of information she has obtained from attending the Cornelia de Lange conference, and from those professionals who work with her son. However, she remarks on her renewed feeling of ignorance when Tom starts school. Fiona refers to the regular multiagency meetings which took place when Tom was at nursery as a means of helping her to understand what was important for Tom's progress. She indicates that she would have liked these to have continued when he started school:

'Because I felt quite… what am I doing here? I wasn't really sure what I was doing.'(Fiona, Tom's mother).

Her quote suggests that times of transitions may mark a new cognitive challenge for parents, when once again, their child's progress is at odds with common expectations of what a child starting school should be able to do and with the learning activities and curriculum on offer at mainstream school. Her phrase '*what am I doing here?'* suggests her renewed feeling of being lost, indicating the need for yet further 'recalibration' of her understanding of her son's development.

3.6.2 Theme 2.2 Emotional Challenge (for mothers and fathers)

The emotional impact of having a child whose development is so distinct from that of typically developing peers separates the parents' learning process from that of the nursery staff. Parents are not just challenged cognitively but are also heavily invested emotionally in learning more about their child. All nine parent participants refer to the affective aspect of their child's development and the impact that this has on them.

Even when the parent participants do not openly express the emotional challenges they have faced, their words belie their true feelings. This is especially true of Jennifer, Joe's mum who emphasises how well her and her husband have coped with their son's autism diagnosis and how her experience as a nursery worker has enabled her to accept the challenges they face as a family:

'*We've actually dealt with Joe's diagnosis really, really well but you just need to, you just need to go with it .. there's no . there's point sitting stressing about something that you can't fix or change.' (Jennifer, mother of Joe.)*

However, embedded within the quote, the vocabulary that she uses suggests that she is putting up an emotional shield as a means of protecting herself and her son, or indeed as a way of hiding the depth of her feelings from others – including her family and professionals. This is reinforced by her repetition of phrases below which also emphasise her lack of control in the situation.

'You just need to get on with it"

'You have to develop a thick skin."

And *'You have no choice.' (Jennifer, mother of Joe)'*

Constantly reflecting on their child's progress and seeking out further information whilst being embedded in an environment which celebrates a linear trajectory of development is described as emotionally very demanding. The following quote highlights how the cognitive challenge faced by Leah's mother, Lesley-Anne, becomes overwhelming:

'Yea it probably tortured me, but yea it's hard because you just, you go into this mode:- I remember at the beginning thinking: 'I need, I'm losing the plot here.' I'd watched every video on YouTube of autistic kids, because, at the beginning I thought 'I'm going nuts.'' (Lesley Anne, Leah's mother).

Lesley Anne's account details how the cognitive challenge that she pursues impacts upon her emotionally and 'consumes' her. Daisy's mother, Sylvie, compares this cognitive and emotional challenge of learning about her daughter's development, with the almost lack of regard which she gave to the development of her older son:

'I didn't have to look in depth at Kyle's development. He did things, that what's he did. He grew up and he did things. Erm so I didn't really need to pay as much attention in that sense of kind of being so permanently on guard if you like, erm…Daisy, it's been a lot of work, I have this kind of, oh, I don't know, the bitter sweet thing where I shouldn't be having to watch out to see if she can manage to do this or assess her development in that I should just be able to raise a child whereas I'm now having to do all of this because of what happened to her at birth and there's the bitter sweet part of it where 'oh that's fantastic she's doing this', and then there's the 'why did I have to wonder if she would.' (Sylvie, Daisy's mother).

Here, Daisy's brother's progress is described as automatic in comparison to that of his sister's. Sylvie uses the metaphor 'on guard' to describe her hypervigilance; - her constant attention to her daughter's behaviour and progress and analysis of this. The oxymoron '*bittersweet'* conveys both her feeling of pride at her daughter's achievement following her brain injury at birth; in contrast to the loss of 'typical development', and the emotional impact that this has had. Her words too, suggest the highs and lows of her daughter's progress, consistent with accounts of 'struggle and progress' portrayed in the study which summarised the experiences of parents of children who had been viewed as exceeding their initial prognosis (Lebeer and Rijke, 2003) Of particular resonance is the following quote:

'I *should just be able raise a child whereas now I'm having to do all of this.'*(Sylvie, Daisy's mother).

This suggests that the experience of loving and supporting the development of a child with complex additional support needs cannot be understood within the parameters of what constitutes or is considered to be 'normal parenting.' Emotionally, perhaps, the participants' experiences are

not solely difficult because of the challenges supporting a child with this level of learning needs, but also because the experience of parenting itself is fundamentally different from that of other parents. This is reiterated by Lucy in the focus group:

'It's a different life. I have three different lives.' (Lucy, Maddie's mother).

Lucy describes these three lives as: the one in which she is herself and doing her job; the one in which she is mother to her typically developing child, and one in which she is mother to Maddie, with complex additional support needs. Here, she describes her role as mother to Maddie as being distinct from the role she assumes when parenting her older child.

The emotional challenge faced by parents is also reiterated in the two focus groups. Perhaps because they have been explicitly asked to give their comments about the emotional challenge that they face, and also because they have gained strength from listening to others who have undergone similar experiences, they are more vociferous in the articulation of their feelings.

'I've been in mourning for a year.' (Lucy, mother of Maddie).

'I've spent so many nights crying.' (Jackie, mother of Olivia).

'It just sort of wafts over you.' (Lucy, mother of Maddie).

The vocabulary employed here by parents is consistent with the theories of 'chronic sorrow' (Kratochvil & Devereux, 1988) and grief stage theories (Ziolko, 1991)and highlights the deep sense of loss associated with their child's disability. Two parents (Lucy and Jackie) highlight too, how this is exacerbated by certain significant life events such the transition of their child to a different school from that of their sibling. This suggests that prevailing cultural norms and expectations serve to exacerbate parents' feeling of loss. The impact of society's non-acceptance of disability on parents' reactions is also highlighted by Bøttcher and Dammeyer (2016) in their cultural historical model of disability, and by Goddard, Lehr and Lapadat (2000), who use a narrative research design to explore views of disability amongst parents of children with a disability.

Although parents highlight the fact that it can be hard to discuss the emotional impact of their child's development, they all refer in the focus groups to the emotional support that they have gained over time from other parents whose children have a similar level of need.

'I think you take a lot of support from other people's battles that are before you.' (Hannah, Emily's mother).

'You met other parents and then you would just say things that you couldn't say to other parents, that they wouldn't get. Then you would just like laugh about it and be like; 'wow, my god someone else actually gets my joke.' (Jackie, Olivia's mother).

Again, these quotes highlight the extent to which their experiences of parents are out with what is considered to be 'the norm'. This suggests that other parents with children with complex additional support needs can at times provide emotional support and incur a sense of belonging which is lost for these parents during other everyday parenting activities.

Whilst nursery staff are aware of the emotional demands on parents, this is only reflected in the interviews of three of the nursery staff participants. They demonstrate an awareness of how difficult it is for parents to understand their children; the frequent comparison of their progress with peers; receiving a diagnosis; meeting the child's learning needs and planning the transition to school. Tricia makes two references to being '*mindful* 'of parents' feelings and trying to be '*supportive'* whilst at the same time highlighting the importance of being open and honest about their child's progress. Throughout her interview, she refers to how difficult it is for parents and demonstrates an understanding of how well Olivia's development is supported by her mother. Staff empathy is further explored in Theme 5.

Mary shows an awareness of both the emotional and cognitive challenge undertaken by Tom's parents and their continual search for more knowledge

'I would say for Tom- they've always had his interests at heart. I think it was them as well, at the start they were relating it to his brother, Gary, they were relating back. They didn't understand it themselves yet whereas, Fiona, like, they go to these annual meeting and things like ...they know a lot about it now and I think that's what has made them like be more open as well coz they understand, they've got more information there now whereas at the start it was maybe trying to process it as well coz it's their child.'(Mary, Tom's keyworker).

The quote also indicates Mary's sense that the parents' increased knowledge has resulted in their increased openness.

Craig, the only father in the participant, offers less detail about the emotional impact of his daughter's diagnosis of Rett syndrome:

'I just kind of get on with it – I've not dealt with it, I don't think'.

His account suggests that he has not articulated – even to himself - how he feels about this. Yet the fact that he acknowledges that he has not dealt with the extent of his daughter's learning needs,

suggests that he feels overwhelmed. It may be that he is managing to support his daughter's needs by not acknowledging his own.

Since Craig presents the only father who was interviewed as part of the research study, and indeed was an involuntary participant in the sense that he agreed to be part of the interview whilst awaiting the arrival of his wife, I felt that it would be beneficial to further explore the role of fathers in supporting their children with complex additional support needs in the context of the focus group. As with the interviews, there were only female participants present.

Both mother participants and one nursery worker echoed similar experiences of fathers to those voiced by Craig:

'He doesn't talk a lot about Emily's Down's syndrome. I think he just goes: 'Well, it's Emily, and that's that.' (Hannah, Emily's mother).

'I'm not saying that he doesn't discuss anything…but he just doesn't seem to want to talk. And sometimes you have to talk. Because I just think... I held it in for a long time when Emily was born and talking does help. And I and my mother will talk about it and sometimes he'll go: 'Oh she's fine'.' (Hannah, Emily's mother).

'I'm obviously a lot more involved than him, he's there in the background. But he definitely wouldn't go and talk to people. He wouldn't have that, he's not that person.' (Lucy, mother of Maddie).

In the focus groups, mother participants refer to the fact that fathers do not talk openly about their child's learning needs, nor do they invest in learning about ways in which to promote their child's progress. In contrast, mothers describe themselves as both the talkers and the 'do-ers'. They report that they are the ones who are actively seeking out knowledge to understand their child's development and who access agencies and groups as a means of promoting their child's development. In contrast, fathers are described as being *'in the background.'*

Yet the mothers' views towards fathers are not necessarily disparaging. One participant, Una, describes the lack of talking as '*self-preservation'* – as a means of keeping things together, for fear that too much emotion will prevent them from coping. Indeed, Craig's own acknowledgement that '*he is not dealing with it'* suggests that what may present as being avoidance, does in fact represent significant 'emotional labour'(Hochschild, 1983). The concept of emotional labour developed by Hochschild (1983) and researched originally in the work setting, proposes that there are cultural emotion norms or 'feeling rules' to be respected, which necessitate individuals to craft means of emotion management to conceal internal discrepancies between their personal feelings and the cultural rules of expressions. Sousa (2015), applied this concept in the educational setting for working class mothers of children with a disability. Her qualitative research highlighted the

unwritten conventions in the educational system which meant that only certain emotions could be displayed according to the role expectations of the parents.

There has been no research conducted on emotional labour involving fathers but Craig's response hints at the fact that fathers of children with a disability may feel they lack permission to talk about or explore how they are feeling, thus making it far more difficult for them to explore both cognitively and emotionally how to best address their child's learning needs. One of the nursery workers reports that she has done research into the role of fathers and consequently, the nursery where she works offers different types interventions as a means of engaging fathers in their child's nursery experiences. Rather than focusing on talking, they offer activities which involve practical work such as contributing to the maintenance of the nursery garden.

The comments indicate that the fathers referred to by the participants address their child's disability very differently from the participating mothers. This has implications not only for future research but perhaps for the types of interventions offered in order to help promote a child's development. How do fathers understand their child if they seek fewer answers about their child's development? Are they more or less likely to adhere to linear models of development? How, too, can they be supported to promote their child's development? This will be further explored in the Conclusion when consideration is given to future research.

3.6.3 Theme 2.3 Diagnosis

The literature on the impact of a diagnosis is conflicting; in one sense, the overuse of diagnosis has been criticised on the basis that it promotes a biomedical understanding of the child and fails to consider the impact of an environment on the child's learning (Llewellyn & Hogan, 2000). Aversion to a label has also been interpreted as a means of promoting normalcy; with a label comes the permanency and the sense of always being out with the realms of what is typical development (Landsman, 2005). Conversely, a label has been interpreted by staff but not by parents as a means of providing further information about a child's profile and securing resources specific to their needs (Lalvani, 2015). Indeed, the use of medical categorisations which have been used in both medical and educational settings have gained more currency and have informed specific strategies based on the profile of this group of learners (Florian and McLaughlin, 2008).

This latter interpretation is more consistent with the views of all participants in this study. The more positive response to a label in this sample may be partially attributable to the significance of the children's difficulties which have meant that there has been less dubiety regarding the nature of the child's needs and which has resulted in all of the children receiving a diagnosis at birth, in infancy or before the age of four. Throughout the interviews, parents and staff indicate that a

diagnosis provides them with more information – this then contributes to further knowledge and understanding of the child.

Nursery staff indicate that a label clarifies the child' needs and helps them to access further support.

'I think it's helpful for having support - you definitely get more help I would say if the label is there… it is good to for you to know what her profile is as a result of that label…. because there's so much you could potentially be putting them at risk if you don't know all that information.' (Pauline, Maddie's keyworker).

Here, Pauline feels that without an understanding of the diagnosis, there is the possibility of failing to meet the child's needs. The nursery staff interviews indicate that knowledge of a child's diagnosis amongst nursery staff varies, especially if the child has a specific aetiology about which less is known. This is what propels staff to do their own research. The accounts suggest that how staff then use their knowledge of a diagnosis to inform their understanding of a child – or indeed their practice - differs.

Lizzie, Ruby's keyworker understands that Ruby has Rett's syndrome yet her description of how this informs her development is vague and she makes no reference to this explicitly informing her practice. Emily's keyworker, Margaret, has obtained information from Down's Syndrome Scotland. This has led to an increased understanding of Emily being a 'visual learner.'

'It's good morning Emily'. She'll put her head down like that. She'll not say it. Children with Down's Syndrome are stubborn.' (Margaret, Emily's keyworker).

However, this quote suggests a tendency to adhere to stereotypes when describing Emily's behaviours and development rather than demonstrating a more individualised understanding of Emily's needs. This contrasts with the staff who support a child with autism and who continue to highlight the individual nature of the child's needs, rather than relying on the label.

'I mean I don't fully understand autism; I'd love to be able to, but you can't – every autistic child is different,' (Vicki, Joe's keyworker).

Perhaps because six of the staff have accessed further training on autism and on teaching approaches which promote the progress of children with a diagnosis, in addition to their experience of supporting more children with an ASD label, they are less likely to adhere to stereotypes and to use a label as a 'short cut' to understanding the child's development. In this sense, aetiology-specific teaching approaches, as recommended by Oliver, Woodcock and Adams (2010) and in accordance with the increasing amount of research on the cognitive profile of children who have the same disorder (e.g. Edwards' Syndrome; Cornelia de Lange) may prove beneficial when supporting

children with the same diagnosis - and if education staff focus at the same time on the individual characteristics of each child. Indeed, the authors suggest that being aware of a child's genetic disorder can be used positively to help understand an individual's presentation; it can potentially reduce the time needed to assess and therefore maximise the potential for early intervention.

The importance of knowing about a diagnosis is again reinforced by the nursery workers attending the focus group. More than the label per se, the participating nursery staff in the focus groups highlight the importance of knowing and understanding the child as an individual:

'I think we should know about conditions before children come in but it's a bigger picture than that, you still have to look at everyone as an individual. The diagnosis is only part of this and contributes to their understanding but should be used alongside the in-depth knowledge obtained from knowing the child well.' (Pauline, Maddie's keyworker).

The quote above suggests the needs to achieve a balance – between understanding how a child's specific aetiology may inform their development, whilst at the same time basing any assessment and strategies on an in-depth knowledge of the child. Interestingly, by emphasising the unique nature of the children's development, the nursery staff recognise and indeed respond positively to 'difference' rather than looking to fit a child's progress within the parameters of what are considered to be the norms of development.

In the individual interviews, all the mothers in the study actively seek out or accept a diagnosis as a way of understanding more about their child and of securing resources; all parents indicate that a final diagnosis can be relief, whilst acknowledging the stressful wait and its emotional impact:

'It was daunting at first, but it was explained... I think it was explained enough to take it in at that moment in time. We were given some information. We were asked not to go away and google it because it's very complex and all the children even at that are different. There was no point in looking and seeing other peoples. Each child is unique so we just, we've left it to be quite honest. So yeah, it was a bit of a relief, as well, at the same time but no. we left that day feeling: "ok, you know, we'll get on with it". (Lucy, Maddie's mother).

Once the diagnosis is given, Lucy indicates that she will not do any further research - that the information given was enough for them to understand their child better whilst at the same time recognising that her daughter's profile would differ from that of other children. Does this mean that in some instances, a diagnosis can result in parents having to do less information seeking or rather, does it mean that they continue to research the child's known aetiology as a means of understanding their child better?

For Lesley-Anne, who describes herself as becoming immersed in the internet, there are mixed and very contradictory emotions about the diagnosis:

'I *went in, I was really upset and said: 'Please tell just tell me, please, I need to hear it from you because I can't go on wondering' because even now I sometimes think, god, I think it might be alright and then other days I think, 'oh this is impossible.' And then he told me; that time it hit me really hard, but I think by the time, I knew what I was going in for in the 4 weeks, do you know what I mean, but I still… even when I was walking in there, I thought, what if speech and language don't agree, maybe it isn't (autism), maybe speech and language are saying that she's fine. I think you do; you just get a bit of kind of, I think you have… a wee bit of hope left.' (Lesley-Anne, Leah's mother).*

Whilst an autism diagnosis brings with it validation of her continual rumination regarding her daughter's development, it also signifies the loss of hope – the hope that she may have been wrong.

For Pam and Craig, the diagnostic process is very difficult. Pam describes Ruby becoming very ill just before her first birthday. This leads to a loss of skills and to the arduous process of seeking support from professionals, and then eventually to a diagnosis.

'It was 4th January 2016 she was diagnosed although we knew prior to that just because well us researching, it took us over a year and a half to actually see a specialist. She took a seizure a day before her first birthday; - she stopped breathing; we took her to the children's hospital and met with the grandparents. They did tests - there was nothing -they just said they took blood tests and will get back in touch. She had a temperature; they never got back to us or anything. She woke up the next morning:-she was unable to feed herself; unable to sit up, it was just constant.' (Pam, Ruby's mother).

Pam's recollection of the precise time of the emergence of her needs, in addition to her use of short sentences to describe her daughter's illness, adds to the immediacy of the passage and reveals the rawness of it for her - and indeed the trauma that they have experienced. Indeed, the diagnosis process is recounted as a flashback memory. For these parents, the diagnostic process is described as necessary, because of the complexity of Ruby's health needs and because her condition is degenerative.

'*We need to know the worst that's going to happen. He's (the doctor) really good with that.* (*Pam, Ruby's mother).*

Here, Pam highlights how 'good' the doctor is who provides her with more information about how Ruby may develop, based on her diagnosis. This is perhaps because it provides her with more knowledge. However, emotionally, the information is difficult to absorb, especially given the

possible developmental regression linked to a diagnosis of Rett syndrome. Her husband, Craig, describes this as being hard to hear.

'Has that been helpful? (*Referring to the Doctor giving them more information about Ruby's diagnosis.)*

'My wife thinks it has but I don't…I find that hard.'(Craig, Ruby's father)

Once again, Craig emphasises the difference between him and his wife Pam's way of coping with incredibly difficult news; whilst he indicates an aversion to hearing about how Ruby's development may evolve, Pam has actively sought out this information. Pam's views are consistent with those of the other participating mothers who seek out a diagnosis and report having an increased knowledge of their child's development as a result. This is in contrast to the feelings of Sylvie who finds the lack of a diagnosis emotionally very difficult – despite the fact she is aware of the brain trauma which resulted in her daughter, Daisy's, learning difficulties.

'I don't want her to have a label:- obviously nobody wants their child to be pigeonholed and be told that erm this is how we're going to deal with her because of this and this and this. Erm you want them to be an individual but at the same time not having that little box ticked means I'm missing out on this, this, this and this in way of support and help erm …. This is where it's becoming very difficult when we're trying to access things, it's almost like it's some sort of secret society in a way.' (Sylvie, Daisy's mother).

The lack of a diagnosis results in Sylvie feeling isolated; her conception is that she is missing out on support and deprived of obtaining a shared understanding of her daughter's development which would come with a diagnosis. Her words ' *this, this and this'* emphasise the amount of support she feels that is lacking as a result of having no widely recognised diagnosis. In addition, the description of support for children with a diagnosis as a '*secret society'* highlights her sense of isolation. Perhaps a diagnosis can at times validate a different development pathway for a child, and a sense of belonging to a much smaller group. Without a diagnosis, the linear trajectory of development remains the only means of conceptualising progress.

3.6.4 Theme 2.4 The Role of Professionals

Being a parent of a child with a significant disability involves continual interaction and dialogue with a range of professionals. Throughout the interviews, parents refer to a range of different multi-agency professionals with whom their child is involved. Their role is integral to the learning process for parents, and for nursery staff.

All nursery staff highlight the positive role that other professionals have in helping them to understand more about the child and to learn how best to support their needs.

Mary highlights the positive impact of working closely with others:

'I've worked really well with the speech and language therapy and O.T (occupational therapy). We've built up that relationship. The collaborative working is the main thing, so long as you're taking your lead from a professional. (Mary, Tom's keyworker).

In addition to emphasising the advantages of collaborative working, the phrase '*taking your lead*' indicates that Mary looks to the multi-agency professional as the experts; their role is to provide more specialised knowledge and understanding of the child. In this respect, Mary emphasises the individual nature of Tom's development since knowledge about his progress and how he may be best supported remains in the domain of 'specialists' rather than being embedded in any cultural understanding of how children with disabilities develop.

The power differential is evident in some of the parents' accounts. All parents indicate that they rely on other professionals to learn about their child. However, parental views about the extent to which professionals from different agencies support them in their understanding of the child varies; whilst all parents obtain reassurance from engaging with some of the professionals involved in supporting their child, four of the parents report occasions when they have felt the need to request more information or when they have not been listened to. There is also a difference between parents in terms of the amount of support they have received. Two of the parents, Jackie and Lucy, are very positive about the range and extent of involvement, compared to others who report that they have lacked enough input from their child – especially in terms of direct input.

Daisy's mother, Sylvie, indicates that she is reliant on multi-agency professionals, both to assess her daughter's development, and to evaluate the impact of suggested strategies on her progress. Without their input, she feels she cannot identify areas upon which to focus. Interestingly, parents' accounts of the different professionals suggest that they are clear about their different roles. More parent participants make positive comments about 'hands-on' advice and strategies that they have received from professionals. Indeed, the parents report the positive impact of the speech and language therapist when they have been directly involved in working with the child or when they have accessed a programme delivered by a speech and language programme which aims to improve a child's ability to communicate:

'*We've just finished doing the More than Words course with a woman called Anna... and she was AMAZING. We've actually kept the book. We've got the book off her... erm because he's only at the stage where he's at... he's just passing the requester stage.' (Jennifer, Joe's mother).*

Yet opinions are different when the contact from professionals is less 'hands on' Without regular input from multi-agency professionals (speech and language therapy and occupational therapy), Sylvie describes herself as being without a 'safety-net' in terms of being able to support her daughter's development.

'She needs more support, I think, in my opinion, more frequent access to the therapists because as I said, I'm left just to 'oh just give us a phone if you've got a problem.' Now that means I often don't know if I've got a problem or not, it means I find it very hard to assess her development with certain things on a shorter-term basis. Now I would expect her to make progress in the three months from one O.T. visit to the next. I want to know that the strategy I've put in place or what they've suggested to me that I've started using is having an effect in the shorter term.' (Sylvie, Daisy's mother).

The contributions from the focus group reinforce the importance that parents continue to attribute to the professionals being actively involved in supporting their child's development, even when this is not always an easy relationship or when parents indicate that they believe that there has not been enough support to help promote their child's progress.

Hannah reports feeling abandoned during her child's infancy

'Sometimes I just felt a bit like they didn't understand.' (Hannah, Emily's mother).

Two of the participating parents report finding the role of the health visitor less useful in supporting their child and describe a lack of contact with them. The demands of the job and the large caseloads mean that health visitors may not always be aware of difficulties in the first instance, unless articulated by the parent or evident during an assessment. Pauline suggests this may be because of their role:

'Health visitors think that their job is to teach us how to change a nappy or come out when it's time to start weaning... whereas it's more of a support thing that you need.' (Pauline, Maddie's keyworker).

This quote highlights the fact that the role of the health visitor is consistent with what support may be appropriate to offer mothers who are parenting a child that is typically developing. Yet, as demonstrated by the views of the participants, their experience of parenting is often completely dissimilar to that of other parents, suggesting that the support offered must also be tailored to fit their needs, rather than based on prevalent cultural parenting practices.

The parents' focus on direct input suggests perhaps that their views of psychological service involvement may not always be positive. Currently, educational psychologists place emphasis on facilitating more effective systemic approaches to promoting a child's development as a means of

ensuring maximum impact and addressing competing demands. This may involve training education staff and coaching and modelling approaches, rather than always working individually with children. The educational psychologist is mentioned by four different mothers on four occasions during the individual interviews. Whilst two refer to the role of the educational psychologist in helping to securing their child a place in appropriate education provision - be it mainstream or specialist provision - Fiona, Tom's mother, refers to the positive impact of strategies highlighted by the psychologist in order to address her son's sensory sensitivities. She also refers to the impact of the meetings organised by the psychologist to ensure that targets in the nursery are being informed by parents and other professionals involved.

'I think because we had all the meetings, erm I think that made a big difference, because they were there then, then everybody was then sort of focused on it, I think without the meetings, with everybody together, it wouldn't have been as good.' (Fiona, Tom's mother).

Here, Fiona's emphasis on the word 'everybody' highlights the importance of working in partnership with both parents and professionals with the aim of focusing on what is important in terms of supporting Tom's progress. In this instance, the educational psychologist's facilitation of the meetings had aided those involved in coming together to focus on this.

This is reinforced by Jackie, in the focus group who highlights the positive impact on her daughter's development when professionals work collaboratively to support the child:

'I found it easier when there was a big connection like me going to the courses, and Susan (the early year's specialist support teacher) going to the courses and then Susan being at nursery and then obviously Susan dealing with you and me and things like that. So, there was a lot of connection.' (Jackie, Olivia's mother).

'I think it helps because you think when all those people are dealing with it all together it just seems easier and more supported.'(Jackie, Olivia's mother).

The repetition of the word '*connection'* and the phrase *'dealing with it all together'* suggest that a sense of shared ownership and an equal relationship have been key to ensuring that Olivia's progress is understood and best supported.

Often parents have sought out advice and support from professionals over and above those they have accessed through health and education. Hannah's responses indicate that she places more emphasis on the information shared by Down's Syndrome Scotland which promotes a linear trajectory of progress and which contrasts with conceptualisations of progress advocated by other professionals who support Emily.

'As I say you could get it from Down's Syndrome Scotland because Jill, the girl who's for us, she has a son with Down's, so I just felt they gave you the better information because they're seeing it from that perspective.'(Hannah, Emily's mother).

The fact that the personal experience of the worker from Down's Syndrome Scotland mirrors Hannah's own, may be why she finds the organisation more helpful – or perhaps more understanding – than other professionals. Yet Hannah's conflicting and muddled accounts of her daughter's development and how she should best promote it continue to permeate her interview and are reflective of the evident contrast in views between professionals and this specialist group. This clarifies why Hannah has been unable to reach any firm understanding of her daughter's development and why, despite involvement from a number of professionals, she reiterates that she would like somebody to help her to understand her daughter's diagnosis.

'*So, we should probably look more now.. her toys are probably quite young. Erm, so it probably is something that we should kind of look and see. And again, you go onto websites and you see the best toys. Like I follow this American man and he tells us some things and his son is a wee bit older so you try and .. but again, it's having somebody… to say 'well see developmentally, this would work, or this would work.' Because, you know, you go, and you buy things and you buy them for her age but sometimes they are too complicated, and she throws them away. But you know, we were told, you stick within her age group'.(Hannah, Emily's mother).*

At this stage, the support Hannah receives from Down's Syndrome Scotland serves to reinforce her adherence to a linear trajectory of progress since they have recommended that she use strategies and toys commensurate with Emily's chronological age.

This is in contrast with the very different account that Hannah gives in the focus group a year later:

'I had Down's Syndrome Scotland telling me, "Oh, you need to put her at her cognitive year." But you can't. I give her toys that are for a four to five-year-old, it's not interesting. But they kept saying, "No, no, you've got to keep her in her cognitive year. You've got to treat her like she is a five-year-old." And I thought, "I can't. So, that is why I had to just step back and say, "No, she's not that….I'm not going to get hung up by the fact that they're saying it's one thing and it's another because I just don't see how they follow that."'(Hannah, Emily's mother).

Hannah's account above highlights that her conceptualisation of her daughter's progress has changed over time and is much clearer since the initial interview took place. Now, she uses toys which motivate Emily, rather than repeatedly trying to engage her with toys that are commensurate with her chronological age. The words: '*I don't see how they follow that'* indicate her rejection of the Down's Syndrome Scotland's worker's promotion of a typical trajectory of development. Her

words also serve to emphasise the confusion that can arise if professionals possess different conceptualisations of a child's progress and are providing parents with conflicting information.

In the interview with Hannah, such had been the level of her confusion over the development of Emily, her daughter with Down's Syndrome, that after the interview and in my role as an educational psychologist, I advocated conducting a criterion referenced assessment that would provide Hannah and her husband with information about their daughter's development in different areas compared to children of the same chronological age. In the focus group Hannah describes this assessment as a turning point:

'And I think that, since I've walked away from that and said, "Right, no, she is not a five-year-old. "She is five, but she doesn't play with five-year-old toys, that's quite acceptable." That is when I went… Right, you can't treat her as her… Is it cognitive age? You can't treat her like that because that report was… It opened my eyes. … So, that is why when you did that report it was: right, we have to realise she is not… She's five but she's two or three in one aspect and she's three or four in another aspect. And I have to walk away from this.' (*Hannah, mother of Emily).*

Indeed, it is only when Hannah can herself make sense of the information she has received and relate it meaningfully to her own child that can she herself conceptualise her daughter's progress. Only at this stage can she begin to see improvement in her daughter's progress and recognise what constitutes meaningful progress for her daughter. Given that Emily is five at the time of the focus group, it may be that Hannah required time to conceptualise her daughter's progress and that a return to the linear trajectory as a gauge of her daughter's progress, eventually enabled her to make sense of and accept ways in which her daughter's development deviates from the line.

According to Landsman (2005), support provided by professionals continues to reinforce a linear narrative of progress, with the aim of interventions being to mitigate disability and to nudge children towards accepted milestones of development. However, the engagement of the participating parents with professionals in this study can also be interpreted as a willingness to understand their child and to involve themselves actively in their progress. Rather than help to promote typical milestones, professionals' engagement with parents is often described in the interviews as helping them to conceptualise progress for their child and to understand their child as an individual, with their own unique trajectory. This is reinforced by some of the programmes accessed by parents which do not attempt to mitigate the disability, but which instead focus on ways of increasing communication -albeit atypical- between parent and child.

3.6.5 Theme 2.5 EYSCY Parent and Child Group (Early Years Supporting Your Child and You)

EYSCY (Early Years Supporting Your Child and You), is mentioned by four of the parents and two of the nursery staff participants. The aim of the group is to provide support and guidance to parents of children under the age of three with complex additional support needs within the context of a toddler group. The group is led by two professionals (myself in my role as an educational psychologist; and a speech and language therapist) but attended by several multiagency professionals on a rolling basis. This includes educational psychology, speech and language therapy, occupational therapy, physiotherapy and early year's workers/specialist support teachers. The aim of the group is to provide an informal setting, facilitated by a number of different professionals, who provide advice whilst scaffolding play and interaction opportunities between the child and parent.

Although there has not been a formal evaluation of the impact of the group and its outcomes on both children and staff, it is mentioned positively without any prompting during the interviews with all parent participants who have attended the group with their child The effectiveness of EYSCY is reiterated and further emphasised within the context of the two focus groups. Three of the four parents attending the focus groups group had participated in EYSCY with their child. Indeed, such is the frequency with which it is referred to in the focus group that its merits its own subtheme.

'That's where EYSCY was good, because it wasn't just about a play group for Daisy, it was about talking to Jo, the social worker, who popped in, or Beatrice the speech and language therapist because maybe there was a problem or this or that. You know, there was people there on a weekly basis, you saw them you said to them' oh, I'm not sure about this that she's doing, that's weird.' Erm or 'I'm trying to find out something about that and now I don't have any of that', … once she started nursery and she was no longer eligible to be in the EYSCY group, everything just, that was it .'(Sylvie, Daisy' s mother).

Sylvie highlights the positive impact of having frequent informal contact with multi-agency professionals about different aspects of her daughter's progress. When this group ended, she lacked the means of gaining a clear understanding about how to understand and promote her daughter's progress.

Lucy, too, refers to the positive social support she received from the other parents whilst Fiona highlights the positive impact of the advice she was given about appropriate toys and motivating activities to encourage her son's engagement. These themes are returned to in the focus group:

'It's breaking down barriers and dealing with professionals before you actually have to deal with them.' (Una, Daisy's keyworker).

'The EYSCY group helped because 'Oh we've got this, or have you tried this....' (Hannah, Emily's mother).

'The nurseries are great, they've got the information, but they don't have all the ins and outs like EYSCY. It's like when social work was there, you could ask them stuff... its support all in the one place.' (Fiona, Tom's mother).

'We've been lucky because we have EYSCY and we speak to other people and they haven't had all that. You're like: "where really would we have been?" Because we have a relationship with you now but if we didn't go to these groups, we wouldn't have had that, which means we wouldn't have had that with Colin (the speech and language therapist) and we wouldn't have had that with anybody else. So, you wouldn't be able to contact you to say: "I've got an issue with this, can you help?" Because we wouldn't really know people.' (Fiona, Tom's mother).

The positive references to EYSCY are reflective of research demonstrating the outcomes of the other programmes, such as the ABA programme, the success of which has been partially attributed to parents' active involvement in their child's development (Von Tetzchner, Verdel, Barstad, Gravås, Jahnsen, et al., 2013). It may be that this is empowering to parents. Significantly, the references to the EYSCY group also indicate that the informal relationships with professionals enable parents to discuss their concerns more freely, in addition to feeling supported to try new activities and interactions with their child. This suggests that where there is less of a power differential, parents feel more able to talk freely and voice their concerns. They may attain a deeper understanding of their child's development as a result. In this sense, the group may concur with several of the aims of parents' groups advocated by Sameroff and Fiese (2000): re-education (teaching parents how to respond to the child) and redefinition (strategies directed towards more optimal interactions through an alteration in beliefs and behaviours).

3.7 Theme 3 Defining Development Differently: Degrees of Insightfulness

The table below details the number of references pertinent to each subtheme made by the participants (referred to in the table as 'sources.') These are further explored in the summary provided below and followed by a more detailed analysis of each subthemes.

Table 9. Number of Interview Sources and References for Subthemes in Theme 3.

	PARENTS		NURSERY STAFF	
SUBTHEME	**Number of Sources**	**References**	**Number of Sources**	**References**
3.1 A DIFFERENT ROUTE	7	35	8	43
LEVEL OF SUPPORT	-	-	6	20
• **difficulty transferring skills**	-	-	5	16
• **difficulty with peers**	-	-	6	11
3.2 UNIQUE AND INDIVIDUAL PROGRESS	6	26	5	20
3.3 RESOLUTION AND INSIGHTFULNESS	9	61	7	65

3.7.1 Summary of Analysis of Theme 3

As indicated in theme 1, cultural norms underpin participants' conceptualisations of the progress of children with complex additional support needs. Linear development provides a starting point, a baseline and a point of reference when trying to make sense of their child's progress. This is consistent with research which suggests that people revert to dominant cultural understandings when expectations about the course of their life are disrupted (Becker, 1997). However, such disruption also leads to a change in understanding, and a break from cultural norms which can be described by participants as illuminating.

In this study, how parents and nursery staff define the development of a child changes over time, because of the learning process in which they engage (Theme 2.1) and as they obtain a more in-depth knowledge of a child. This process is depicted in participants' accounts as being dynamic and results in a continuum of views. Thus, the extent to which the participants adhere to linear narratives of progress or describe their child as taking a different route – e.g. following a delayed or different route, (seven parents and eight nursery staff), or indeed abandon this discourse altogether (six parents and five nursery staff describe their child's progress as being 'unique') results

in contradictory conceptualisations, both between the two groups of participants and within groups (e.g. within the parents' accounts). Even within an individual's account, a participant's description of a child's development can wander back and forth between linear/nonlinear accounts.

This highlights the difficulty of rejecting such discourse when it is culturally pervasive and when there is no other discourse available. It also produces ongoing conflict throughout the accounts – since the linear trajectory continues to be what most of the parents aspire to or how progress is defined within the context of nursery curriculum. To reject this discourse - or indeed be rejected by it - represents a loss of status for both the parent and the child. However, those who describe and celebrate more specific examples of what could be deemed to be atypical examples of development, present as having a clearer conceptualisation of their child's progress. All nine participants can give examples of their child's atypical progress and demonstrate a degree of 'insightfulness' in terms of understanding their child's motivators and individual likes and dislikes. However, there is a difference in the extent to which parent participants can do this. In the focus group, however, there are more evident examples of parents celebrating atypical examples of progress.

3.8 Analysis of Subthemes

3.8.1 Theme 3.1 A Different Route

Whilst all participants highlight the fact that the child's development differs from that of typically developing peers, as indicated in Theme 1, they continue to use the linear trajectory as a baseline and a comparator. This is unsurprising given that parents and staff lack a framework with which to gauge their child's progress. Parents and staff continue to use chronological norms to compare their child's progress with typical milestones – often to highlight the extent to which the child is delayed or behind his or her peers. Thus, a child's progress is conceptualised as following the typical trajectory but at a slower pace. This is consistent with other research: in the qualitative studies conducted by Becker in which parents were interviewed about making sense of their infant child's progress within an intensive baby unit in hospital (Becker, 1997), the data suggested a shift in focus from an absolute timeline to the plotting of their child's relative progress along a linear developmental stage. In this study, this shift is described as occurring over time, as adults engage in the process of learning about their child.

Lucy can reflect on how her attitude to her daughter's progress has changed in terms of both the focus and pace:

'I felt before, we were, you were, we were running away ...and she wasn't doing these things and you were trying to get her to do other things and not realising that she needed to get her to crack that first. (Lucy, Maddie's mother).

The word 'delayed' or 'behind' is used by four parents and five nursery staff and is consistent with diagnostic language (e.g. global developmental delay) and with Zigler's 2-structure model of disability (Burack et al., 2012), which proposes that children with no specific aetiology may go through the same universal stages of development as typically developing children but at a slower rate and with a lower ceiling. Landsman (2005) recounts that delayed development can be emotionally easier to deal with since it is still tied up with notions of progress and moving forward. It also makes it easier to conceptualise progress since the understood norms of development can be used as a reference point.

'She's beginning to shuffle around on her bottom. She can't crawl yet and we think she might miss that stage out. We don't know if she'll ever be able to walk, (Pauline, Maddie's keyworker).

Here, Pauline makes references to typical stages of development when describing Maddie's progress; she also suggests that she would find it more appropriate to refer to the curriculum for younger children as a means of finding a more appropriate measure to assess the progress of children with severe needs, indicating that their progress is conceptualised as being delayed:

'It would maybe be… probably be much more practical to go back and use.. like we've got our sheets that monitor all the progress of and if we're seeing like obviously, I'm talking now 0-3 where we can say oh they can kick a ball, they can do this, that would have probably been much more appropriate. For the ASN children that I worked with in the 3-5 room because the Curriculum for Excellence is- there's a lot of it was way past their development already.' (Pauline, Maddie's keyworker)

Conceptualising progress as being 'delayed' can also leave open the possibility of catching up. Hannah suggests that obtaining further information about where different aspects of her daughter's development are in comparison to chronological norms will allow them to focus on *'making her up to 5'* or to accepting the fact that '*she'll always be a year behind.'* As detailed in Theme 2, Hannah initially interprets delayed development to mean that there is a possibility that her daughter will 'catch up'.

In addition to the use of the terms 'delayed' or 'behind', participants use other terms to describe the children's progress. These highlight differences in their development compared to typically developing peers, but also continue to plot their development on a line – albeit a non-typical one. For example, progress is referred to as being '*up and down'*; '*stop and start'*; *'spikey'*.

'She'll make, you know, a certain amount of progress and then she goes backwards and then it's a little bit step forward again and then it's a little bit backwards.' (Margaret, Emily's keyworker).

'Between here and home, she can be different at home to here as well with some of the things we've been saying that are maybe not happening at home' (Jane, Leah's keyworker).

Jackie, Olivas's mother, highlights her different skills levels in different areas of development. She describes Olivia's very 'spikey' profile, consistent with her ASD diagnosis:

'She's four obviously, but the way she does certain things, like a 2-year-old. You know what I mean like...? So …I think that, even though she's 4, she's still at that 2-year-old stage where you know, 'it's mine', and. like a kind of toddler ...and how to .... you know, like get... taking turns and things like that.' (Jackie, Olivia's mother).

This contrasts with her physical development:

'Physically, she can do so much. And you know she is so precise. You know, I think she could even go on a tight rope... you know physically that's how physically, Olivia is like amazing, she's just so precise, you know, she's, I've had a lot of trust in Olivia, even just walking up and down the stairs since she was very young.'(Jackie, Olivia's mother).

In this account, there is still a tendency to refer to chronological norms, and presume delayed development, even though Jackie's description of her daughter's development is consistent with it being disordered, rather than delayed. Thus, there is continual conflict between notions of linear trajectory embedded within western notions of activity and progress, and between the individual and different nature of this child's development.

Nursery staff also refer to other aspects of the children's learning which help to identify shared characteristics demonstrated by this group or learners. This is a means of establishing ways to support their progress within a nursery setting. For example, five members of nursery staff highlight the children's difficulty transferring skills to a different environment; six also highlight their difficulty interacting with peers and six refer to the level of support children with this level of needs require to carry out learning activities and to manage the nursery environment. This emphasises the staff' awareness of the different environmental factors which may facilitate or impede a child's learning within a nursery context and also highlights the difficulty children with this level of need have when alongside peers. These examples are also suggestive of ways in which progress can be noted in a more lateral way – rather than being consistent with a linear trajectory. (For example, by noting the number of environments in which a child can demonstrate a skill, or the level of support required).

3.8.2 Theme 3.2 Unique and Individual Progress

Whilst continuing to compare them to their peers, five parents and five of the nursery staff repeatedly refer to their child's development as being *'unique'* and '*individual'*. There is repeated reference to the child learning *'in his own wee way.'* This awareness of the individualised nature of their development marks a move away from initial expectations about how they will progress. This is consistent with existing literature that suggests that at the outset, parents adhere to the linear trajectory of development but that they may reach an eventual acceptance of their child and of their non-normative qualities (Goddard, Lehr and Lapadat, 2000).

Lucy describes the change as she has come to accept her daughter's development:

'Six months ago, I would have cried my eyes out every night but now I just think, well ...you know, she's sitting and she's fine. So, I did, it was hard, but I got, you know, you have the little red book and all the little milestones and none of that was there and what I've just done now. I've scored all that out and I just write the date and the age of when she's hit that, and I can see her progress coming from there it doesn't matter and she's doing that in her own time.' (Lucy, Maddie's mother).

The rubbing out of the standard milestones in the red book given to mothers at the time of a child's birth provides a powerful metaphor and signifies Lucy's rejection of the linear trajectory of development and her focus on her daughter as an individual. However, it is also worth noting that Maddie's development is described throughout the interview as delayed - implying that she is demonstrating progress but at a slower rate. Thus, perhaps, this metaphorical rejection of the typical trajectory is easier to embrace.

Fiona is constantly compelled to compare her son's progress to the typical milestones and to that of his peers, and his brother, but despite this, she is cognisant of the fact that for Tom, the only constructive comparison is with himself and how his presentation has changed over time.

'You're obviously comparing all the time … I mean you compare him where to where Gary was all the time, but you can only compare him to himself.' (Fiona, Tom's mother).

Nursery staff participants reflect on the fact that their understanding of the child's development has changed as they have obtained a more in-depth understanding of the child. Nursery staff who have had previous experience of working in this sector, also highlight the individual nature of the development of all the children with whom they have worked with this level of needs. Their experience has resulted in them addressing their child's needs on an individual basis, rather than defining them purely by their disorder or label or by expecting them to adhere to chronological norms.

'I think you can't have a kind of expectation of how a child with autism is going to behave or going to ...you've just got to see them as an individual and their own wee needs and.... what they require from us can be different.' (Vicki, Joe's keyworker).

'I think it's so important I think it's so important that you get it right for every child that you're working with and you see children as individuals and what works for one child isn't going to work for the next child.' (Jane, Leah's previous keyworker).

Jane, who works in the ASN nursery, uses the word 'stage' on eighteen occasions, but she does so to refer to aspects of development pertinent to a child with severe autism. E.g. she refers to the 'object of reference stage' to indicate the point at which the child can recognise one or two objects to signify another object or action; she also refers to Leah's communication being at a 'pre-intentional communication stage.'

'But also, we've had the odd occasion where there has been the odd word as well, it might be 'ball', it might be 'go', but not, not consistent, but again I think before you get to that stage, just even copying her babbling that she does, getting eye contact.' (Jane, Leah's previous keyworker).

Jane's quotes suggest that she possesses a more individualistic notion of what constitutes progress for this child - perhaps borne out of her experience of working in this sector and the training she has accessed - and she uses the vocabulary of progress in a way that is individualised and meaningful for this child. In addition, she describes following the lead of the child, rather than adhering to a predetermined set of steps and she identifies 'stages' that are meaningful to Leah.

The quotes above highlight the importance attributed to getting to know the child and to understanding that each child will progress differently, despite their diagnosis. The staff quoted here have all had experience of working with children with this level of needs and highlight the importance of tailoring their approaches to the child.

In the focus group, both parents and nursery staff participants refer more consistently to the child being an individual and make fewer references to them following the typical trajectory – albeit delayed. This marks a more evident shift in the thinking of participants. Indeed, the word individual is mentioned on fourteen occasions by participants in the two focus groups.

In the quotes below, both of which are from the focus groups, a child's individuality is also described by two of the mothers in positive terms:

'Of course, Maddie's case, it's so individual, you've not got constraints that this will happen, and this will happen, you've got to think of her as 100% individual taking things at her level.' (Lucy, Maddie's mother).

'Olivia is so individual that I had to learn from her, you know, I had to go with Olivia and what she was doing because that's the way Olivia is.' (Jackie, Olivia's mother).

Jackie describes learning from her child whilst Lucy refers to the linear trajectory for the first time in negative terms - as being constraining, signifying her increasing acceptance of her child's individual trajectory.

3.8.3 Theme 3.3 Insightfulness and Resolution

Whilst all parents and nursery staff can give examples of progress which would be considered 'atypical' or very delayed, the number of specific examples they can give of a child's progress or the extent to which they can talk in detail about or indeed celebrate individual aspects of the child's progress varies. There are fewer examples of this during the interviews, suggesting, perhaps, that the embracing of non-normative qualities is not easily achieved during the early years of a child's life. In the interviews, two of the parent participants (Hannah and Fiona) also find it difficult to identify their child's strengths when they are asked and require prompting to do so.

The accounts suggest that those parents who can provide more detailed descriptions of their child's progress - even when it is considered to be atypical – and highlight strengths and weaknesses may be more 'insightful.' According to Oppenheim and Koren-Karie's definition (2002), parental insightfulness is the ability to be able to maintain an emotionally complex view of the child, considering his or her motives for behaviours, and individual likes and dislikes. Insightful parents are described as being able to see things from the child's point of view and being aware of their own feelings when faced with new information about their child. As referenced in the literature review, insightfulness for parents of children with complex additional support needs could be considered to be evident in the extent to which they can celebrate atypical examples of their child's development and be clear about what constitutes progress (Feniger-Schaal, Oppenheim, Koren-Karie, & Yirmiya, 2012).

In the study, insightfulness appears to be more difficult to achieve for parents and nursery staff supporting the progress of those children whose development remains very atypical and when there are very infrequent indicators of any progress. Whilst Lesley-Anne can identify several examples of progress for her daughter, Leah, which may be considered atypical (e.g. *'she no longer jumps on her knees and can jump on her feet'*), she understandably finds it very difficult to celebrate progress when it is often fleeting and inconsistent.

'I can see that's a bit better, but apart from that, I mean that's what Callum said as well, if we could go every 6 months (to see the paediatrician) and we could say, do you know what, it's getting a bit better, but we can't, and I

think that's the hardest as well, coz you think that 6 months, it seems like yesterday. What's happened in that 6 months? Nothing…whereas your neurotypical child would come on leaps and bounds probably at that age.' (Lesley-Anne, Leah's mother).

She highlights the lack of progress over a long period of time and makes a comparison to 'neurotypical' children. Her difficulty identifying progress is also explained by the fact that she is still struggling very much to accept her daughter's diagnosis and deviance from the norm.

'*I don't think anything would make me happy, apart from Leah not having autism and it's very hard to just see it because I just don't want it, I just don't want her to have it.'(Lesley-Anne, Leah's mother).*

This contrasts with Jackie, who makes frequent reference to specific and often atypical examples of the progress of her daughter, Olivia, despite the fact that she is only a year older than Leah, and also has an autism diagnosis with similar learning needs. This will be further explored below.

Ruby's parents, too find it very difficult to have a clear conceptualisation of her progress, given that she has very complex additional support needs and complex health needs. They refer to a process of elimination that they go through in order to try to interpret what her needs are, including checking Ruby's stomach, checking her nappy, and checking that she is seated correctly.

'But communication wise, we've got no idea what she knows or doesn't know.' (Pam, Ruby's mother)

Interestingly, however, both parents give examples of ways in which Ruby's communication has improved, albeit atypically, and despite the fact that they do not label this explicitly as progress:

'I mean she can now recognise our voices, we know that so if Craig is on her phone and if I put him on the loud speaker she's like that, looking at the doors, and the smile, and the smile, and her wee arms .. so you know she'll get a wee bit excited.'(Pam, mother of Ruby).

Within the focus group setting, the increased focus on the child as an individual led me to ask the participants if they now found it easier to identify specific progress for their child. All parent participants agreed and gave examples of the child's progress – all of which could be plotted on a different pathway. There were also fewer examples of development being described as delayed, indicating perhaps that parents were focusing more on what they deemed to be important for their individual child's progress without comparing them to peers.

'She's actually learning to sit down and stuff like that for two minutes and it's just amazing.' (Jackie, Olivia's mother).

'It's Tom, he says, 'aye'. He can't talk but he can say that. (Fiona, Tom's mother).

'She'll play with what she wants to play with. If it's a three-year-old toy, it's a three-year-old toy.'(Hannah, Emily's mother.)

Nursery staff 's recognition of progress varies, although it can be anticipated that this is easier to achieve, given the fact that staff are less emotionally involved and consequently, perhaps less intent on adhering to a linear trajectory. However, Pauline, Maddie's keyworker, describes finding it difficult to be clear about what constitutes progress for children with very profound needs. Whilst she celebrates Maddie's 'delayed yet linear' progress, this contrasts with her description of her experience of working young children with profound needs.

'*Like I worked in an ASN nursery …I've got to be honest, I really struggled in the baby room in there because I did feel, that job is actually more of a nurse, when I was there anyway. Personally, you weren't really educating the child or necessarily progressing them, it was very much more ... a nurse's job of like using their equipment and looking out for sign of a seizure.' (Pauline, Lucy's keyworker).*

Because of the significance of the children's associated health needs, Pauline reports that she did not feel that she was involved in promoting their progress. To some extent, this is reiterated by Ruby's mother, Pam, who highlights that her focus is on supporting her daughter's health needs, rather than her development.

'I'm not concerned, you know, I mean I'm not concerned if she does recognise me or not … for me it's about making sure her health, for me it a priority that her sores or her chest or whatever is my priority for her. That she's got the best possible life.'(Pam, Ruby's mother).

Jane and Lizzie, both of whom work in the ASN nursery, have worked hard over a longer period to gain insightfulness and to conceptualise the progress of children with profound needs. For Lizzie, she is aware of the difficulty of this and reports that she has asked for support from a team member when target setting for Ruby. She also recognises the importance of spending time observing her after a period of absence. These responses to children with very profound needs are consistent with the transactional model of development (Sameroff & Fiese, 2000) which highlights the impact of the child's presentation on adult responses and interactions. If adults struggle to understand the meaning of a child's atypical responses or to perceive the child as an actor who 'affords' a response from the adult, (Bøttcher & Dammeyer, 2016; Bang, 2009). It is perhaps much more unlikely that they will succeed in planning learning activities according to the child's needs.

Bøttcher and Dammeyer (2016) highlight the importance of following a child's motives, which are reported to develop and change as the cognitive and emotional abilities of the child change. The interviews contain several references to following the child's lead and examples of motivators

which parents use as a means of increasing their interaction with the child, or as engaging them in activity.

'We started copying everything that she did and that made such a difference. I wouldn't have even though to do that ...like and it made such a huge difference for Olivia. As soon as she realised we were there, and we were copying what she was doing, it was like all of a sudden it just opened up this world of communication for her.' (Jackie, Olivia's mother).

'Numbers seem to be his favourite thing... so, we've put... he never ever played with any of his construction toys but once we put numbers on his ... he loved them. (Jennifer, Joe's mother).

Jackie takes advice from the speech and language therapist and succeeds in achieving more attuned interaction with Oliva by following her lead, rather than trying to direct the interaction. Similarly, Jennifer adapts her son's toys to increase his engagement and enjoyment. By taking the child's perspective, it becomes possible to share attention, emotions, objects and minds (Lorenzen, 1998 in Bøttcher & Dammeyer, 2016; p85).

Jackie, Olivia's mother, can describe and celebrate her daughter's progress, albeit it very atypical. Although her daughter has few motivators that are described as changing very frequently, Jackie uses her daughter's recognised motivators as a 'hook', and as a means of encouraging her interaction. Parental insightfulness may therefore be dependent upon the ability to reject the linear model of development to some extent and the accounts suggest that an increasing knowledge of a child leads to far less reliance on cultural norms of development. The fact that they are not as emotionally invested in the linear trajectory may explain why nursery staff report more instances of a child's 'atypical' motivators than parent participants. All staff highlight the importance of using sensory motivators as a means of promoting engagement or interaction. Similarly, six nursery staff report employing physical motivators.

'That was developed with the shadowing remember, there was just do you know, shadows came in through windows with the sunshine and she loved if you made shapes in the wall, just really building her engagement all the time by looking at it was interesting for her.' (Una, Daisy's keyworker.)

These stimuli are not necessarily used in a conventional way but are based on an understanding of the child; what motivates them, and, in some cases, what calms them down.

In the focus group, nursery staff too, echo the views of the participating mothers and do not refer to having to try to meet a child's needs within the context of the normal nursery environment or

the curriculum. In this group setting, they present as more confident about meeting a child's individual needs.

'It's that old cliché, you don't judge a frog on how well it can climb a tree.'(Una, Daisy's keyworker)

'It's focusing on what they're good at, what they enjoy, what they're going to do at that moment in time.' (Pauline, Maddie's keyworker).

Here, Una's use of a cliché emphasises the importance of judging a child's progress based on an understanding of their individual needs rather than on cultural norms. Pauline's quote then provides an example of how this understanding of the unique development of the child is applied to practice by focusing on the child's motivators. Indeed, the use of motivators provides a means of encouraging the child to express their likes and enjoyments, thus contributing to their sense of agency.

It may be that parents who can celebrate their child's atypical progress and who could be deemed 'insightful' are also more 'resolved.' Research into parental resolution highlighted that mothers classified as resolved to their child's disability were more likely to match their behaviour to their child's strengths and weaknesses (Marvin & Pianta, 1996).

Jackie's account indicates not only her level of insightfulness, but also her resolution of her daughter's learning needs, prompted, perhaps by her experience with her older son who also demonstrates social communication difficulties.

'With Olivia I'm not so sure about Olivia. I would never say never, and I don't want.. What I try to do is, I don't put any pressure on me or on her.. I don't think: 'Oh she is going to talk; she's not going to talk.' I don't think like that. We just, like you say, we just be glad for the progress that we make and we just you know, we praise that when we get it and we are happy that we get it, and we work on the stuff that isn't there.'(Jackie, Olivia's mother).

It may be the case that more insightful parents were more eager to participate in the focus group. After being presented with the main themes that had emerged from the interview data, the participating parents were explicitly asked about how they had come to this increased acceptance of their child's individuality, given the fact that the linear trajectory of development is so embedded within our cultural understandings of what constitutes development for a young child.

'It's one of the hardest things to get out of your head... you feel sick to the bone looking at it and thinking 'oh god , all these children are doing this, and it's taken a long time to get out of that.' (Lucy, Maddie's mother).

The 'red book' is a big thing, but you overcome that, don't you?' (Lucy, Maddie's mother).

'We just have to wait and see what road he wants to be going down, like where he will get to, like with the support he'll get.' (Fiona, Tom's mother).

'I think one of the things we did was just learn to take each day at a time. Because every day is different. (Jackie, Olivia's mother).

The quotes above highlight the continuing emotional challenge of rejecting cultural norms and suggest that the relation between parental insightfulness and resolution is complicated and tempered by cultural notions of what is deemed to be acceptable progress. Thus, if a linear trajectory of progress is reinforced by common cultural understandings of what is perceived to be normal development, it may be very difficult to accept alternative conceptualisations of progress and to achieve resolution. In addition, given the fact that the participants' views change over time, and in response to significant transitions, it can be assumed that the extent to which they attain resolution or demonstrate insightfulness of their child's development may also change in accordance with these.

As in the interview, Lucy continues to use the metaphor of the 'red book' given to a mother at a child's birth to signify her eventual rejection of the typical milestones that are recorded within it. At the same time, there is an acknowledgement amongst parents that with the passing of time, they feel more able to follow their child's lead and to focus more on what they are doing now, rather than projecting into the future: Quotes such as: '*we just have to wait and see'* and '*we take each day at a time*' echo this and are reminiscent of the research conducted with parents of older children with disability in which parents' viewed their child's outcomes as open-ended and multiply determined (Lebeer and Rijke, 2003).

Hannah's increased insightfulness is marked by a rejection of the linear trajectory which she describes as being endorsed by Down's Syndrome Scotland:

'So, if somebody tells me she's playing with this and it's a three-year-old toy, I'll play with it. I'll not go out and buy a four and five to six.' (Hannah, Emily's mother).

'That was one of the biggest and best things I did was just then to allow her to make her moves at her time, when she was stable, ready. And you think you've mastered something and then the next day that would be gone again and so, you just need to revisit and redo it again. Or three weeks later it might come back, or it might never come back.' (Hannah, Emily's mother).

For Hannah, her rejection of the linear trajectory has led to a change in the activities she uses to support her child's progress, in addition to an increased acceptance of what constitutes progress:

The quotes above focus on her daughter's inconsistent progress, and indeed sometimes a plateauing or regression. Yet her account suggests Hannah's increased acceptance of this.

Jackie, whose contribution in the focus group indicates both her insightfulness and also her resolution of her daughter's complex additional support needs, describes the positive side of 'breaking free' from the red book.

'Do you know, it just gets to a point when it's just like this is your new normal and your normal is not, nothing in that red book can like you know, make her normal.'… It's nice to break away from that and be happy in that situation' (Jackie, Olivia's mother).

'We don't live waiting for her to talk, we don't expect for her to say a word. It would be lovely if she did, but we don't put our hopes on it. What we do is just we just concentrate on what she can do now, and just make the most of that because I am just not wasting any more of my time... her childhood worrying about what she's going to do.. what's she's not going to do…' (Jackie, Olivia's mother).

Here, Jackie not only accepts and celebrates her daughter's strengths and difficulties but describes her daughter's development as being her new 'norm' (she repeats the word 'normal' on three occasions, emphasising both the pressure exerted by societal norms of development and also the liberation she feels at 'breaking free' from these). Rather than remaining future focused and predicting what Olivia will do based on general assumptions of the milestones a child should reach, Jackie concentrates instead on the 'here and now'. It is not clear how Jackie so successfully manages to reject dominant cultural norms and achieve such resolution, given the extent of her daughter's difficulties. Indeed, her celebration of her daughter's atypical examples of progress contrasts with Lesley-Anne's difficulty eliciting any signs of her daughter, Leah's, progress, despite the fact that s she also has a similar profile of needs. One factor which may contribute to this high level of insightfulness could be the close and positive collaborative relationship between Jackie and those professionals supporting Olivia. This will be further explored in Theme 5.

3.9 Theme 4 Focusing on 'the Basics' (interviews only)

The table below details the number of references pertinent to each subtheme made by the participants (referred to in the table as 'sources').

These are further explored in the summary provided below and followed by a more detailed analysis of each subtheme.

Table 10. Number of Interview Sources and References for Subthemes in Theme 4.

	PARENTS		NURSERY STAFF	
SUBTHEME	**Number of Sources**	**References**	**Number of Sources**	**References**
4.1.THE BASICS: • ***self-care and independence***	4	7	7	17
• ***physical***	3	8	6	11
• ***calm and happy***	4	6	6	11
• ***academic versus the basics***			2	
4.2 COMMUNICATION EXPRESSIVE SPEECH BEHAVIOUR	9 5 2	46 15 8	8 5	98 10
4.2)MAKATON	4	7	5	16
4.3 OTHER/DIVERSE STRATEGIES MOTIVATORS	8	84 (to 12 different approaches)	8	68(to 13 different approaches)

3.9.1 Summary of Analysis of Theme 4

A summary of the analysis of the themes is provided below, followed by a more in-depth analysis of each of the subthemes.

As evidenced in table 7, participants in both groups identify common and key areas of progress (communication; physical skills; self-care and independence; being calm and happy) which they believe are important and constitute 'the basics' for children with complex additional support needs. Consistent with their role, nursery staff make more explicit references to the child's development. Their accounts also contain fewer references to the emotional impact of the child's

development than are evident in parents' accounts. Repeatedly, all parents and nursery staff identify the development of the child's communication as being of utmost importance and reiterate this during the focus groups. 'Communication' thus constitutes a separate subtheme although there are differences in terms of which aspects of communication participants deem to be the most important. For example, five parents place continued emphasis on developing their child's expressive speech skills, whilst nursery staff refer more frequently to the development of children's social communication. The shared emphasis on communication may explain why there are seven references by four of the parents to the use of Makaton, the language programme which uses signs and symbols to ameliorate the communication skills of children with learning difficulties. Five nursery staff also refer to the approach.

Nursery staff accounts indicate that the focus for progress is based on a more in depth understanding of the child, despite the imposed use of a tracking tool which follows the milestones of typically developing children. Yet cultural norms of development result in contradictory accounts and there is an evident dichotomy between a focus on individual needs, versus adherence to a linear trajectory of progress. The vocabulary used by two of the nursery staff demonstrates that they are still influenced by cultural notions of progress; they refer to 'the basics' (communication; independence etc.) versus 'academic skills' (literacy and numeracy skills emphasised by the curriculum). Five of the nursery staff - compared with two of the parent participants, also highlight a focus on addressing behaviours that are deemed to be challenging. In these instances, they are described separately from a child's communication and influenced by cultural norms of what behaviours are deemed to be typical for a child of a certain age.

Although many strategies to promote progress are referred to by both groups of participants, these are not similar across the two participant groups – nor is there evidence of any explicit strategy or teaching approach being used consistently or with a set outcome in mind. Indeed, there is no further reference to different strategies during the focus group. With the exception of Makaton, this suggests that neither parents nor nursery workers adopt specific teaching approaches or interventions which they believe will better promote the progress of a child. It is not clear whether this is because they are uncertain about the focus of progress, and what will constitute progress for the children, or because they lack knowledge about what strategies they should use to support their child's development.

3.10 Analysis of Theme 4 Subthemes

3.10.1 Theme 4.1 The Basics' versus 'The Academic.'

Further analysis of the interview data indicated that the key areas for focus (highlighted in the table above) are influenced by the child's needs. For example, for Maddie, who has significant mobility issues, her mother focuses on the development of her physical skills and is able to detail specific progress in this area:

'She'll kind of commando roll over but we're trying now to get her up and shuffle over.' (Lucy, Maddie's mother).

'Even though she's sitting really well she still goes down but in a way, she's going down safely.. which was a big thing for us because before she would just drop back so the head was whacked off the floor or toy ,everything around the house was padded.. you know there's cushions. This is getting less and less which is really good.' (Lucy, Maddie's mother).

Fiona is able to highlight Tom's increased independence and self-care needs:

'He still needs help dressing and things like that, but he does want to give it a shot himself. He'll try and put his shoes and things on - even some clothes and things he can manage himself ..he still needs a wee bit of help.' (Fiona, Tom's mother).

For Ruby, given the significance of her needs, it is unsurprising that her health is of utmost importance to her mother, Pam, rather than her cognitive development:

'*For me it's about making sure her health for me it's a priority that her sores or her chest or whatever is my priority for her,' (Pam, Ruby's mother).*

On three occasions, two nursery staff refer to the curriculum – to the learning of ' academic' skills or 'education' skills, versus a focus on the 'basics'.

'Even though she needs a lot of support... just simple things. We're still trying to do that whole education part of it where she's learning like her colours and basic Maths and basic literacy and stuff. Again, with Emily, even just learning to recognise her name.' (Margaret, Emily's keyworker).

'Academically, I was working with her erm with Makaton trying to do colours and just the kind of basics and things like that, but she wasn't ready for that, she wasn't ready.' (Margaret, Emily's keyworker).

In these two quotes, Margaret reports on her attempts to focus on the development of skills typically acquired during the preschool years. Whilst she recognises the futility of focusing on colours, there is an indication that staff are continuing to focus on counting with Emily, despite their awareness of the fact that she does not yet have any number concepts. This suggests that

there may be a pressure to carry out activities which are deemed 'age appropriate' (e.g. fit with chronological norms) for typically developing children but which are not commensurate with the ability of a child with complex additional support needs. Interestingly, Margaret refers to this as '*the whole education part of it',* insinuating that that key areas of focus for Emily do not fit with a general understanding of what children should learn within the sphere of the curriculum.

This is reinforced by Vicki, Joe's keyworker:

'And then the more I've learned about it, the more I've learned like no, not every child is at the stage where they are ready to learn the academic part of life.'(Vicki, Joe's keyworker).

The above quotes suggest that the concept of education is inextricably linked to the linear trajectory of development. Even when staff can determine what should be a focus for a child with complex additional support needs, this does not necessarily result in them equating this with constituting an 'education.' This may be reinforced by the curriculum, the principal areas of which are 'literacy and numeracy', consistent with the cultural importance attributed to these skills. It also suggests perhaps the lack of importance associated with those skills that are identified by the participants as being key to promoting the progress of children with complex additional support needs. Although a focus on physical skills and independence skills is still acceptable within nursery provision given the developmental norms of younger children, does this make it more difficult for schools to feel confident about focusing on these areas, despite the needs of this group of learners?

For four of the nursery staff, their understanding of progress as being atypical or individual is marked by their rejection of the nursery tracking tool and by their understanding that the Curriculum for Excellence must be adapted and individualised to meet a child's needs.

Vicki rejects the curriculum in its present form altogether in the three quotes below:

'So, I find the Curriculum for Excellence, for children with as profound needs as Joe, it does not support that in any way.' (Vicki, Joe's keyworker).

'I wouldn't even to say to go on the younger one (curriculum), that's not totally relevant to his development as well because he's not developing neurotypically - he's developing in his own individual way.' (Vicki, Joe's keyworker).

'Even the curriculum as a whole- I don't think its individual enough for each child coz well maybe one child can't count to ten, maybe they can write their name before they are 3, I don't, I just don't think of whatever else children can do, it should be a bonus, its shouldn't be about well, this is what they need to do before they, no. ... every child's different. I mean that's pressure for the nursery.' (*Vicki, Joe's keyworker).*

She describes the focus of the curriculum as consistent with the linear development and rate of typically developing children. Yet for the participating staff, the focus for progress is consistent with those key areas identified within the South Lanarkshire Framework for supporting pupils with complex additional support needs (Rees, Tully & Ferguson, 2017) and reflective of the curricular approaches advocated by Imray and Hinchcliffe (2014); these emphasise the importance of implementing a curriculum which focuses on a smaller range of key areas. This promulgates an individualised approach to both target setting and progress and a narrower focus than those areas identified by the Curriculum for Excellence.

3.10.2 Theme 4.2 Communication

All participants refer to the importance of the child's communication skills on many occasions. This is consistent with what would be deemed to be a priority for the development of typically developing children. It is also consistent with other research which highlights the importance of the development of communication skills across all disabilities (Spiker, Boyce & Boyce, 2002) and the relation between communication and long term outcomes for the child (Chapman, KayRaining Bird, Burack, Hodapp, Iarocci, & Zigler, 2012). However, there is a difference in terms of the focus; whilst six nursery staff emphasise the importance of developing a child's social communication skills, two of the parent participants focus on the development of their child's understanding, and five parents continue to focus on their child's expressive speech.

Although there is an understanding in some cases that a child's behaviours are indicative of their communicative attempts, the accounts are contradictory. As in Theme 1, there is still a tendency to attribute agency to a behaviour which is deemed challenging within the context of nursery and to view a child's behaviour as separate from a child's communication. Whilst only two parents refer to working on their child's behaviours, five nursery staff refer to addressing the child's behaviours in the nursery setting as being of importance. Yet, at times, behaviours continue to be judged within the parameters of those deemed to be acceptable of a typically developing child of the same age. This indicates that the nursery setting, and cultural expectations of how children should engage within such a setting can present major barriers to individual behaviours being thoroughly assessed as a means of understanding the functions that they serve for the child.

For some parents, broadening their child's communication skills is their aim – so that their child can be understood and can interact with others. For two of the parents whose children have an autism diagnosis, they emphasise their wish for their child to have a better understanding. Daisy's mother refers to the fact that people find it difficult to communicate or understand her child because she uses atypical means of communication:

'I have to prompt other people... I don't know why other people find it so difficult- I find it obvious.' (Sylvie, Daisy's mother).

Her quote suggests that only those with a relationship with Daisy and who possess an in-depth knowledge of her needs, can interpret her communicative attempts and thus develop her communicative skills. This highlights the importance not only of knowing the child but also of individualising strategies based on this knowledge.

Five of the parents continue to focus on expressive speech as being an identified priority for their child.

'Really our main thing is, we want him, we want him talking. That's the ... we would rather everything concentrated on this.' (Fiona, Tom's mother).

'She says 'mum' a lot.. that's the only one consistent word that she has.. so, I'm like she can do it .., it's just (pause)and sometimes I'm like .. is she just? I don't want her to get too comfortable using objects of reference.' (Jackie, Olivia's mother).

'Probably when she would say stuff, like she would say the odd words, yes that's one of the big things.' (Lesley Anne, Leah's mother).

'We've tried, it with her we've said to her; 'right we're not moving until you've said the word' but instead she will try and do a sign, or she will try and kind of say something.' (Hannah, Olivia's mother).'

These quotes indicate the strong wish for the majority of parents to focus on furthering their child's expressive communication, even for children who are currently largely nonverbal. This differs from the accounts of nursery staff who highlight the importance of social communication skills such as turn-taking.

The difference between nursery staff and parental responses demonstrates perhaps the influence of affective factors on what is deemed initially important for a child's development. For any parent, being able to communicate with their child is of utmost importance yet this requires a child to engage in reciprocal interaction with the parent. When the mother views her child as a communicative partner, this results in a more facilitative interaction style (Tulkin & Cohler, 1973), and indeed, forms the basis of the attachment between the parent and child. When a child does not demonstrate these anticipated behaviours, it becomes much more difficult for a parent to know how to initiate effective interaction. Although, in the interviews and the focus groups, there was no explicit reference to the impact of the child's communication skills and disability on the

parent/child relationship, the parents' desire to focus on their child's expressive skills demonstrates their continual quest for their child to be able to communicate more fully with them.

3.10.3 Theme 4.3 Makaton

Makaton, the language programme which uses signs and symbols to help children with additional support needs to communicate, is the only specific strategy highlighted consistently by both parents and staff (it is referred to by four of the parents and five of the nursery staff). This is consistent with the importance attributed to developing a child's means of communication - particularly expressive communication - and provides a tangible means of working on these key skills. It is also perhaps reflective of the direct input provided by the speech and language therapist. Indeed, Makaton is referred to by those parents and professionals who reside in an area where the speech and language therapist is highly trained in the approach, and where he has delivered training to nursery staff and has followed this up with further coaching. The impact of this training and its application is evidenced in the participants' comments. Yet although Makaton is referenced in research as being an intervention employed frequently to ameliorate the communication skills of children with complex additional support needs, particularly those under the age of seven, there is much less current research on its impact on individual children's skills (Hooper & Walker, 2002; Lindsay, Dockrell, Law, Roulstone & Vignoles, 2012).

3.10.4 Theme 4.4 Diverse Strategies

With the exception of Makaton, there are no common or universal strategies or approaches being employed by the majority of participants. Many strategies and approaches are mentioned, but none of them by more than three participants in each of the two participant groups. These are grouped together to form one subtheme and include: modelling; use of visuals; intensive interaction; repetition; building on a skill; 'hand over hand'; following the child's lead; giving a choice; chaining.

Instead, parents place emphasis on using a child's motivators as a means of engaging and interacting with their child (There are 21 references made by parents to using motivators). This includes music and dance (three parents) and the use of numbers (four parents).

'She loves and really responds to anything musical - songs and dance - songs with actions we really became aware of this at the EYSCY group, so she likes doing routines, dance routines type things so if it's something like the Wiggles or Mr Tumbles song, or this or that, she loves doing that kind of thing. It really grabs her (Hannah, Emily's mother).

Motivators are described as providing a means of engaging a child's interest and interaction and furthering their developing. The examples given also highlight individual children's sense of

agency. According to Landsman (2005), agency is attributed to a sense of personhood so valued in western culture. However, promoting a sense of agency using motivators can be considered integral to promoting a child's development and provides a way of enabling a child with complex additional support needs to communicate their likes and express enjoyment. Indeed, looking for opportunities for a child to demonstrate a sense of agency, using a motivator as a hook, differs from the analysis in Theme 1.1 when participants afforded a child agency and attributed volition to their behaviour, rather than conducting an assessment of the functions of that behaviour for the child. According to Wehmeyer, Shogren, Palmer, Williams-Diehm, Little et al., (2012), an aim for teachers of pupils with complex additional support needs should be able to enable students to act volitionally and to become causal agents in their lives, using their motivators a means of facilitating this. However, at the same time, further consideration should be given to the extent to which notions of agency are intertwined with western notions of personhood; promoting a child's agency should first and foremost serve a positive and meaningful function for the child.

Interestingly, throughout both parents and nursery staff accounts, there are several references to a variety of strategies which participants have employed to promote the child's progress. Yet the accounts highlight a lack of consensus about approaches to promote the progress of this group of learners. This finding corresponds with the earlier paper by Norwich and Lewis (2001) who indicated that the strategies employed to promote the development of children with complex additional support needs are based on the same principles and approaches as those employed with typically developing children. Conversely, with the exception of Intensive Interaction, it could be that parents and education staff use diverse strategies because they lack knowledge of approaches that have been developed specifically for children with complex additional support needs. This is consistent with the lack of evaluative research into the effectiveness of specially developed teaching approaches (Lacey, 2011).

3.11 Theme 5: The Relationship between Parents and Nursery Staff; trying to get 'on the same page'

The table below details the number of references pertinent to each subtheme made by the participants (referred to in the table as 'sources.') These are further explored in the summary provided below and followed by a more detailed analysis of each subtheme.

Table 11. Number of Interview Sources and References for Subthemes in Theme 5

	PARENTS		**NURSERY STAFF**	
SUBTHEME	**Number of Sources**		**References**	
5.1. DIFFERENT CONCEPTUALISATIONS OF PROGRESS	7	53	1	1
5.2. WORKING TOGETHER TO UNDERSTAND CONCEPTUALISATIONS OF DEVELOPMENT	8	54	8	36

3.11.1. Summary of Analysis of Theme 5

In this study, all participants (nursery staff and parents) refer to the importance of the relationship between home and school in supporting the child's progress. In other research, (Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005), eliciting the views of parents of children with complex additional support needs regarding their wishes, needs and satisfaction with provision, is seen as an important first step. Yet Bøttcher and Dammeyer (2016) suggest that 'developmental incongruence' may occur for the first time in a child's education when nursery practices such as the teaching approaches and curriculum, do not meet a child's individual learning needs. This is further confounded by the main themes of the present study which highlight that cultural notions of progress, in addition to individual experience and the presentation of the child, may influence how a child's development is viewed. In addition, the data suggests that such views may change over time, and also at significant times in the child's life, such as at times of transition.

In the accounts of both staff and parents, different conceptualisations of progress have a bearing on the relationship between parents and nursery. Interestingly, whilst seven parents make fifty-three references to their views of their child's development contradicting those of nursery staff, only one member of nursery staff alludes to a difference in opinion. This suggests that either staff hesitate to mention more difficult dialogue in the context of the research, or that they are unaware of the parents' views and feelings. In contrast, both groups of participants (eight parents and eight

nursery staff) make a number of references to instances when they share the same views about the child's development and about what constitute important areas of progress for the child.

3.12 Analysis of Theme 5 Subthemes

3.12.1 Theme 5.1 Different Conceptualisations of Progress

Nursery staff participants highlight the importance of establishing a positive, open and equal relationship with parents. Yet, as emphasised in research describing parents' experiences (Goddard, Lehr & Lapadat, 2000), this may be very difficult to do if teachers subscribe to dominant cultural codes which pathologise parents.

Two of the mothers highlight their reticence about talking with staff:

'I know, that is it's really hard, it is really hard. Sometimes you just feel as if they kind of you think, I've dealt with it, we've dealt with it before so, do you know what I mean? It's hard it is it's hard. I mean Ethan goes to school and they don't even hear from me and everything's fine but when they've got additional needs, its different isn't it?' (Lesley-Anne, Leah's mother)

'I feel like I'm having to tell them stuff and then sometimes I feel you try and talk to the teachers as a mother, what she likes, and what she doesn't like whatever and they just try and kind of 'well, we'll suss it out.' (Sylvie, Daisy's mother).

Both accounts highlight that parents are reluctant to talk openly and initiate discussion for fear of being judged or dismissed, or for fear that their role as a mother may be minimised. Indeed, in five of the interviews, there is an assumption by nursery staff that parents 'are on the same page' regarding their child's progress without this having been explored or explicitly checked out by nursery staff. Five of the nursery participants report positive relationships and a shared understanding of the child's progress which is contradicted in the corresponding parents' account. Even when a parent may express positive views about their relationship with nursery staff, five parents have conflicting views about their child's progress of which nursery staff are unaware. In addition, nursery staff may also not always be cognisant of the negative impact that their feedback may have on parents' own views about their child's progress and their own role in supporting this.

For example, Mary, Emily's keyworker, highlights to Emily's mother, Hannah, that Emily demonstrates more skills in the nursery environment. Yet she fails to emphasise the fact that children with complex additional support needs are likely to have difficulty transferring skills to a different environment. Without this acknowledgement, Hannah's interview suggests that she may perceive her daughter's success in nursery as a recognition of her own difficulty in promoting her progress at home.

'Mm we're trying to focus on the same things, erm we're also we're trying the toilet training. It seems to go not too bad here (at nursery) ...but not at home. ….but we're like, we're changing what we're doing to what the nursery's doing ...we're trying that. She seems to develop …As I'm saying... she seems to develop more here (at nursery).' (Hannah, Emily's mother).

The account of Emily's more evident progress in the nursery environment appears to disempower her in her own role in promoting Emily's progress. Hannah is trying to follow the nursery's lead as a result and reiterates the fact that her daughter seems to be developing more in the nursery environment.

Jane, Leah's keyworker, highlights the importance of indicating 'tiny steps' and reminding parents what progress their child has made. She indicates that she believes Lesley-Anne, Leah's mother, to be happy with the focus and outcomes:

'Certainly, the feedback she has given us through, you know she's looked at, for example, Leah's learning profile book, where we ask for parents' comments on that, the feedback we've had through consultations has all been very positive. We keep her up to date with where we are with the targets set for her. Again, we've had her ASP review meeting which mum came to. Again, it's another opportunity to express how she's feeling.' Her mother I think overall, she is pleased with the progress.' (Jane, Leah's previous keyworker).

This contrasts with Lesley-Anne's views; she demonstrates a very different and far less clear conceptualisation of what progress is for her daughter.

'I just can't be bothered with trying to make everything rosy when it's not and it frustrates the life out of me. One of the biggest things probably why nursery is driving me nuts, its 'How did Leah get on? "Yea, she had a good day.'. I know, that's maybe a good day to them but it's not a good day to me and don't try and make, me, do you know what I mean? A lot of the time, I just think, for example, She sat at the snack table today for 10 seconds as well I don't want her just to sit at a snack table for ten seconds, do you know what I mean? I don't see how that,.. so sometimes I think what they see is like a step forward as a step forward, sometimes, I don't really think it is, do you know what I mean? Is this… how bad this is, that is what you need to pick out to Leah's progress, do you know what I mean? Stuff like that … And if she doesn't, I just want them to say; 'no, she can't tolerate it' and 'we really need to work towards this', do you know what I mean? - instead of staying to me, 'oh, well.…'I can remember when I got told her targets thinking: 'this is so unfair, I can't believe how little these are' (Lesley Anne, Leah's mother).'

Whilst nursery have broken targets down and are setting very small targets, Lesley-Anne rejects these and finds it hard to consider that such small steps constitute progress. This suggests that she may continue to adhere more to a typical trajectory of development in terms of both pace as well as direction. In addition, she conceives the nursery's approach as a glib attempt to highlight

positives. For Lesley-Anne, this only serves to emphasise just how significant her daughter's needs are and the extent to which Leah's development deviates from the norm. However, her daughter's targets are presented to her at the Additional Support Plan meeting, rather than being the result of initial discussion and a chance to share and discuss conceptualisations of progress. There has thus been no real dialogue and collaboration, perhaps exacerbating what are already conflicting views of progress.

Other accounts from both staff and parents demonstrate that a more equal relationship is facilitated by open and frequent communication:

'Lots of speaking to mother daily, lots of feedback erm every day.'(Margaret, Emily's keyworker).

'I think in the past I've been very …I've had ... it has been a positive relationship, so they've felt they could contact me if they were anxious about something. And I've never felt really that I've really been holding back. I think just you know there's always that positive relationship, trust where you're making that regular communication, they're getting to know you, so I think I've always been as honest, as you can be.' (Jane, Leah's previous keyworker).

'Yeah, yeah, we discuss it; we discuss what they're going to be working on. They let me know I work on the same things at home. Obviously, there's some discrepancy there because its nursery and it's at home so there is going to be things that are different but in general we try to work on the same things here that we do there, and the nursery are great at supporting you that way so that when you're working on something you're not alone ...like they'll keep doing it here... I think that's very important as well.' (Jackie, Olivia's keyworker).

In the above quotes, this communication includes being honest, not necessarily just agreeing but engaging in frequent and open discussion and accepting a possible difference in opinion. Interestingly, Jane, Leah's keyworker, emphasises the importance of this yet nursery practice (e.g. writing the child's plan and targets prior to inviting parents in to discuss it) may impede this. A shared understanding of the child's development is likely therefore to be a result of in-depth dialogue during which conceptualisations can be tested out and explored by both parties. Yet if there is a perceived power imbalance, the opportunity for this to happen may be infrequent and may at times be exacerbated by formal education processes such as review meetings.

The accounts indicate that the role of the keyworker is pivotal in enabling more in-depth dialogue. A change in staff can result in staff and parents becoming very quickly misaligned if their conceptualisations of progress are markedly different and if these have not been explored together. Una, Daisy's keyworker, highlights the negative impact on both Daisy and her mother after a change of key worker. Whilst Una had ensured that there had been very frequent and open dialogue

with mother about Daisy's progress, the new keyworker is described as lacking experience of working with children with this level of need.

'*I just built up that relationship where I knew exactly what Daisy was doing, the same as she (Sylvie) did, so she knew, if I could see something that she could act on it, that it wasn't just something on a whim, kind of thing, and I think that's been difficult for her, not having me to speak to. I think she's just looking for the reassurance, that her wee girl is doing the best that the possibly can be and to see her regressing with changes in the nursery. I think it'll take her a wee while to get over that.' (Una, Daisy's keyworker).*

Here, Una describes her understanding and in-depth knowledge being on a par with that of Daisy's mother, Sylvie. She describes the new worker as not providing Sylvie with reassurance. Significantly, she refers to the fact that Daisy's progress has regressed as a result of this change. Indeed, this suggests that without a shared understanding of what constitutes development for the child, and without working collaboratively to promote this, a child may not make progress. This is exacerbated by the fact that the new worker has no experience of working with children with complex additional support needs– and her conceptualisations of progress continue to adhere to that of a typically developing child.

'She's going by the book, not by the Daisy…not by Daisy, not by understanding Daisy's needs. (Sylvie, Daisy's mother)

'She's kind of she's halfway between following the book rigidly and when she has modified a target she's modified it to be so ridiculously low that's its demeaning to Daisy to think she can't cope with more than that. Because if she's given the right direction and the right support she can cope with more than that erm but that's something I haven't been able to have a proper talk with the keyworker about the targets and that's another problem with it being just the job share and two days a week and all the rest of it is that I haven't had the opportunity to sit down - its 6 weeks since the new session at least - it must be about 6-8 weeks - and I still haven't had a proper discussion about targets. Now if you're going to have to rewrite targets for somebody, you're leaving out the most important person there by not giving the parent, the main caregiver, any say or an opinion or anything else." (Sylvie, Daisy's mother).

Here, Sylvie uses a metaphor '*going by the book rigidly'* to describe the new keyworker's adherence to a linear trajectory and to what are perceived to be 'typical milestones'. This is in direct contrast to her tendency then to set targets that are '*ridiculously low'*. This perhaps indicates the keyworker's uncertainty; her difficulty understanding what constitutes progress for Daisy, and her lack of understanding of how the type and level of support provided for Daisy can have a significant positive impact on her performance and ability. The accounts also highlight the importance of planning transitions carefully; discussion about minimising developmental incongruence should

therefore not only include a focus on the environment and on practices used but also on an exploration of the views of those vested in supporting the child's development.

3.12.2 Theme 5.2 Working Together to Understand Conceptualisations of Development

More positive relationships are described when staff demonstrate an understanding of the emotional impact of the child's learning on their parents and when there is a shared ownership: those parents and staff who have worked together to arrive at a shared understanding of the child's progress - or to accept that they may have different perspectives - share a more equal relationship and sense of focus.

Jackie's account indicates that she is able to maintain ownership of her daughter's learning, whilst recognising that the focus may be different in the nursery environment.

'Nursery has mirrored what I've been doing. That has made such a big difference for Olivia.' (Jackie, Olivia's mother).

Her sense of ownership and empowerment are evident in the language she uses. On three occasions, she uses the word 'mirrored' when describing how nursery staff take their lead from her and apply the same strategies to the nursery environment. A significant number of studies demonstrate the importance of parents of a child with a disability feeling empowered about their child. Effective relationships between parents and professionals are therefore likely to have empowering benefits for the parents (e.g. Dempsey and Dunst, 2004). In samples of parents with a child with a disability from Australia and India, (Dempsey, Foreman, Sharma, Khanna, and Arora, 2001), the authors found that an enabling family-professional relationship was a significant predictor of empowerment over and above both the personal characteristics and socio-economic status of participants. Feeling empowered may be especially important within this context when parenting child with a disability results in a loss of both status and control. Indeed, there is some research that indicates that the sense of feeling control is directly and positively correlated with their judgements about their parenting capabilities(Dunst & Dempsey, 2007).

For Lucy, nursery staff have assisted her in redefining progress with the targets after she had thrown away the red book containing the milestones:

'I find it easier. Much easier. Erm I think as well because they all have a little.., they all have a plan. I suppose I didn't have a plan before - like the milestone thing- I had to stop the plan. So, it's been quite nice and it's only very…the plan is.,, just you know, to get her sitting still, it's not a plan way up to when she's going to be 3, which I felt was really running away. So just having a small plan and being able to.....I think that has helped in that I've

got no qualms I suppose about saying things. Not that I dislike anything but yea, I just say it now' (Lucy's, Maddie's mother).

Lucy feels that this plan is consistent with how she now views her daughter's progress and that nursery staff have enabled her to identify smaller and more realistic targets for Maddie. She also reports that she would still feel able to indicate if she disagreed with nursery staff.

Jackie portrays the hard work of Olivia's keyworker and how she repeatedly came to her to talk over strategies and progress:

'At Xmas when she did the nativity, coz I was really worried about it and Tricia was working with her really hard and it got to the point that see just before it, Tricia would come to me and tell me her thoughts: 'Right, this is what we've been doing, and this is how Olivia is reacting. This is how I think we should do it. What do you think?' And each time I was just happy to do it because I think that they were spot on, and it was because we all worked together. Especially in nursery because they're all so aware of her and their understanding of Olivia and what she needs and how not to put any pressure on her and we tried just not to get her upset.' (Jackie, Olivia's mother).

Here, Jackie gives examples of dialogue between herself and the keyworker which are reflective of a more equal relationship; when Tricia makes a suggestion, she checks out Jackie's view first. Jackie's use of the third person pronoun 'we' also portrays her sense of working collaboratively with the nursery to support her daughter's progress.

Tricia's views about working with the parents of children with complex additional support needs echo Jackie's description:

'Again, we're so lucky in nursery because we can have a daily relationship with these parents, and we can be supportive... to them.. so, we're very lucky where we can be speaking to them. I know like maybe the base does their home diary and things like that but I'm just thinking like the rest of the children, we can still have that relationship. Erm I think it's about kind of the building up the trust with them and offering them as much support as we can erm and trying to get them to do these courses and things like that if they've not done it and trying to get them through the stage of seeing that their targets are small but for that child, that is their target, you know, rather than them kind of getting upset about what they can't do. It's about us helping them focus on what they are doing and things like that you know what they are achieving because it can be really difficult for them.' (Tricia, Olivia's keyworker).

In the quote above, Tricia conveys an understanding of the emotional impact of a child's development on the parents. She also demonstrates a sensitivity and awareness of the difficulty of discussing targets which parents may perceive to be very small. For Tricia, working towards a shared conceptualisation of development involves not only building an open and honest

relationship, but supporting parents to access programmes and other means of understanding their child's progress;- all of which can contribute to a parent recognising the significance of the progress that their child has made. Tricia is cognisant of the fact that what she understands to be progress for Olivia may differ from her mother, Jackie's, views. However, this does not pose a barrier nor prevent close working. Instead, Tricia's awareness of this and sensitivity results in her placing considerable effort in supporting parents, building up trust and ensuring that they can access courses which may contribute to them understanding their child and their child's progress.

Perhaps because the focus groups are comprised of both parents and nursery staff and provide a safe setting in which to articulate views, both sets of participants explore what constitutes effective and joined up support for a nursery child with complex additional support needs This forms a core part of the discussion. As in the interviews, nursery staff participants emphasise the importance of relational factors; they describe working with a child with this level of needs as requiring the establishment of a close relationship with the family.

'When you're working with a child with additional support needs, you're not working with that child, and you're working with that family and the whole community that is round about that child.' (Jackie, Maddie's keyworker).

Jackie here demonstrates an understanding of working with the team around the child.

'I think that's where the support, the relationship, being good and being able to talk with them... We can reassure you that no, you're not asking too much. It is our job. If that helps you worry about something less.' (Jackie, Maddie's keyworker).

Indeed, she reassures Lucy when she questions whether she is asking too much of nursery staff by meeting the complex needs of her daughter. Interestingly, the very fact that Lucy seeks reassurance hints at her unease about asking nursery staff to provide a level of support to her child that is not considered to be the norm.

It may be that this power differential lessens when a member of nursery staff possesses a deeper understanding of a child's learning needs. Both parents and nursery staff emphasise the importance of support staff being individually selected to support the learning needs of the child. Significantly, however, participants indicate that to acquire such skills, support assistants and nursery staff require qualities that cannot always be learned as a result of training. The word 'passion' is used on five occasions and 'compassion' on nine occasions in the second focus group. These qualities are described as being integral to providing effective successful support.

'I definitely think that people that work with children with special needs have to have compassion. They have to have a realisation of it. You can't just go, "Oh, I'm going to be an assistant" and that's that. I think you've got to have more to you than just.; "That's what I want to do." You've got to have … been involved in it, I think' (Una, Daisy's keyworker).

'I've took up all the training opportunities, autistic children, children with Down's because I had worked with another child with Down's syndrome before I worked with Emily. And I had just taken because I'm really passionate about all children, I had just taken that… "Oh, I need to get some training because this child is coming through and I don't know much about this condition." (Margaret, Emily's keyworker)

'I think you (nursery management) need to be able to have that compassion as well and realise who needs what. It's like building strengths and weaknesses,' (Una, Daisy's keyworker).

This 'compassion' is linked to staff possessing the drive and motivation to learn more about the child and to seek training when they need it; it also ensures that management can effectively match a nursery worker with a child, dependent upon the individual needs of the child and also on the training needs of the staff. According to Una, this compassion is borne out of empathy and a deep understanding of both the child and parents:

'A twenty-year-old that has probably not been through it isn't going to have the feelings that we have. Whereas, I think if the care workers or the support workers or any of the workers have been in the situation or have people around them that are the same, they're going to have compassion for them.' (Una, Daisy's keyworker).

Una suggests that this level of empathy may arise from having been in a similar situation to that of the parents. There has been very little exploration of nursery staff and teacher empathy. In a small-scale study conducted by Broomhead (2013), parents indicated that they felt only those teachers who had their own personal experience of supporting a child with ASN demonstrated a true understanding of the affective factors involved with parenting their child. Broomhead (2013) tried to increase empathy by involving a parent of a child with disabilities in pre-service teacher training. As a result, positive feedback was obtained from student teachers, in terms of how the parents' accounts had developed their understanding of parental perspectives, encouraged empathy and would inform their practice. Yet further research is needed to increase staff understanding of parental perceptions and to explore how such knowledge can have a direct and positive impact on practice.

Jackie, who has established a close rapport with Tricia, her daughter's keyworker, encapsulates this level of empathy in the following quote:

'You're their champion but then there's somebody else that wants to be their champion as well and you're just like. 'Wow."(Jackie, Olivia's mother).

Here, she equates Tricia's drive to promote her daughter's progress with that of her own, signifying shared ownership and close collaboration. They are both, equally, Olivia's champion. Interestingly both Jackie and Tricia can give a number of examples of (often atypical) progress that Olivia has made since starting nursery. Could it be that this close and equal collaboration leads not only to a shared understanding of a child's development, but also to both parties being able to highlight very specific examples of progress? Significantly, it may be this close and equal working partnership has an indirect and positive impact on Olivia's continual development.

CHAPTER 4 CONCLUSION

4.1 Summary of Main Findings

The conclusion considers the main findings of the research study, in addition to methodological decisions and limitations. This is then followed by implications for practice and considerations of ways in which educational psychologists can work collaboratively with both nursery staff and parents to obtain in-depth and ecological understandings of the development of a young child with complex additional support needs. A joint intervention is also proposed which aims to facilitate closer and more equitable working between parents. There are then further recommendations for future research.

The research findings indicate that understandings of the development of a young child with complex additional support needs are constructed culturally, relationally, and individually as a result of dominant norms of development and personal and relational knowledge of the child. These understandings are mediated by the language used to describe the child's needs and by the power relationships between parents and professionals. They are also dynamic since these personal meanings may change over time and in response to different factors at the level of the individual child, family, nursery setting and culture. For example, how development is conceptualised may change in response to the relationship with the child, and with those who support the child's development, in addition to perceived significant culturally determined transition points in a child's life. The outcomes therefore advocate the adoption of an integrated understanding of the development of a child with complex additional support needs which takes into account cultural norm, a child's diagnosis, and their functioning and participation in different contexts.

The main findings are summarised below.

4.1.2 The Influence of Cultural Norms and Existing Power Differentials

Whilst I had hypothesised that different conceptualisations of development would be informed by different models of disability at a societal, institutional and individual level (e.g. the curriculum and the current policy of inclusion promulgated by the social model; versus the focus on impairment highlighted by the medical model) the views of both parents and nursery staff fluctuated over time and oscillated between the medical and social model. Of particular note was the fact that participants' views were consistently influenced by assumed norms of development, and by linear narratives of progress that are informed by dominant theories of development. Indeed, the views of the participants suggest that rather than being distinct and promoting different views of progress, the two ostensibly opposing models of disability are in fact intertwined;- they both fail to embrace difference and continue to inadvertently endorse cultural norms of development which assume a linear trajectory of progress. Whilst the medical model focuses primarily on impairment and on the extent to which children's development deviates from

presumed norms, the social model highlights the extent to which societal barriers are created by a focus on this norm. Indeed, both the parents and nursery staff indicate that the social model, operationalised in the form of the Curriculum for Excellence (Scottish Government, 2009), downplays the impact of a child's impairment by failing to promote further understanding of ways in which a child's disorder or learning difficulties influence individual development.

Such is the pervasiveness of a linear trajectory of development that any progress which is seen to deviate significantly from this norm, results in a lack of knowledge, at least initially. At times, this leads to a polarisation of views regarding how the child will develop:- describing a child as understanding 'nothing or everything'; or making progress according to a linear trajectory, versus making no progress at all - is an effort to make sense of the child's development using the cultural resources available. Over time, participants report a recalibration of their views and sometimes an acceptance or indeed celebration of their child's atypical development. These views may be further revised at periods of transition in a child's life, such as starting nursery or school. For example, this is evident when one of the parents, Fiona, discusses her son, Tom, starting school;- a new stage in life about which there are explicit cultural expectations, reinforced by the curriculum of what a child should attain by each stage.

These cultural norms are also embedded within the language used to describe children's progress in the interviews and give rise to the use of particular discourse, e.g. '*moving forward*'; '*reaching a milestone'*, which denotes an onwards journey. As is evidenced throughout the analysis of the interviews, there is a significant relationship between social constructions of progress and the operation of power. Constructions related to a linear trajectory of progress are more dominant in society, opening up certain ways of seeing the world, making them seem the more obvious and the 'right' ones. These examples are peppered throughout and embedded within the main themes, thus forming an important component of the overarching principal theme: 'The Influence of Dominant Cultural Norms; Linear Trajectory.' This explains why, despite the influence of Vygotsky's zone of proximal development (Bruner, 1984), and the importance of scaffolding a child's development based on individual need and presentation, both parents and nursery staff continue to revert back to the discourse of linear progress and commonly accepted 'milestones' when talking about the development of children with complex additional support needs.

Supporting a child whose development does not adhere to cultural norms leads to the parent participants failing to meet common expectations of themselves as parents which results in both a loss of status and power. The data highlights the existence of different and interrelated examples of negative power differentials which renounce the status of both the child and their parent. There

are examples of what Landsman (2005) refers to as 'reduced motherhood' throughout. The outcomes also suggest that 'resolution', defined as the ability to have incorporated their child's diagnosis and the impact of this into their interpretation of the child on a long-term basis, may fluctuate over time or indeed may be very difficult to attain given the pervasiveness of societal norms which continue to reinforce negative attitudes towards difference.

Yet the research data indicates that the majority of the participating parents are eventually able to renounce the linear trajectory of development to some extent – and for periods of time - as parents get to know their child and are able to focus more on their individual and sometimes atypical aspects of their progress and what is important for them. Indeed, examples of progress are more evident in the focus groups which occur between seven to twelve months after the individual interviews. However, without an alternative framework, both parents and nursery staff continue to use the linear trajectory to consider the extent to which the child deviates from this 'line' or shows forward movement in one aspect of their development but not in another. Rather than denoting progress as continuously moving forward, their progress is described as 'on and off', 'stop and start' being 'behind'. The linear trajectory thus serves as a comparator and allows participants to move towards more individual notions of progress. This can then provide a meaningful and positive way of helping to conceptualise individual progress.

Despite previous research which renounces an overreliance on the use of medical categorisations, in this study, both parents and nursery staff find a label of descriptor a useful way to both understand and make sense of their child's developmental trajectory – and at times, also to find some sense of belonging to another, smaller group. Interestingly, the one parent whose child lacks a more definitive diagnosis, describes feeling lost and excluded from any group. The focus group context, too, provides a shared experience and an opportunity to talk about aspects of a child's development and experiences that are shared by all those present. According to Becker (2005), individual views of normalcy are reshaped in groups. Indeed, within the context of the groups, all participants redefine what is considered to be normal development for their children and talk more freely and acceptingly about examples of progress which they would consider to be atypical in another context. They also gain support and therefore status within this group. Interestingly within this context, and away from overarching societal norms, it becomes easier for parents to accept difference. This highlights, again, the extent to which conceptualisations of progress for young children with complex additional support needs are dependent upon context and are constructed both relationally and culturally.

4.1.3 Working Together

According to Landsman:

'the disabled child's personhood, largely negated by society, emerges in the relationship with the mother and so too a mother's transformed self emerges in the relationship with the child.' (Landsman, 2005, p2).

Similarly, this relationship between key worker and child leads to an in-depth knowledge of the child, and an ability to see and celebrate progress. At the same time, it is very unlikely that the nursery worker will be overwhelmed by the emotive aspects that can take their toll on parents. In this sense, nursery workers can be pivotal in helping parents to see individual strengths. The outcomes of the research indicate that progress of a child is more apparent - or at least more frequently acknowledged - when those who support the child share conceptualisations of development and work together closely. This is more evident when there is not only a close relationship between parents and nursery staff but when their accounts indicate that this is an equal relationship - when parents can talk freely and openly (e.g. Dunst, Trivette & Hamby, 2007). Indeed, the accounts suggest that the existence of embedded power differentials, which are not made explicit, can prevent parents from articulating their views in the presence of nursery staff.

In the focus groups, individual nursery staff's interest in working with children with this level of need is particularly important in terms of the emphasis supporting the development of a child. In addition, reference is made to the empathy demonstrated by some nursey staff - an ability to comprehend the emotional impact on parents of their child's needs - and to convey this in a sensitive and supportive way. In the study, several participants referred to their own life experiences (their son's illness; their cousin's disability) which explains their level of understanding and which may have informed their approach to supporting a child. It appears from the qualitative data that this leads to a closer relationship between parents and staff, which in turn informs closer collaborative working and a shared understanding of a child's development.

The outcomes of the study highlight the importance of recognising the individual nature of the child's development, without being constrained by a curriculum that better meets the needs of a typically developing nursery population - whilst at the same time using what would be perceived to be a linear trajectory as a baseline of how a typically developing child may progress. At the same time, there is enough reference to similarities in terms of how this group of learners learn (e.g. through the use of motivators) and what the focus should be for development (e.g. communication; self-care and independence) which indicate that it may be appropriate to identify these common aspects as a means of developing teaching strategies and curriculum content which can further the development of all or most children with complex additional support needs. This

fits with a 'generalised differences' position which advocates the use of teaching approaches which. Meet the needs of all children with complex additional support needs.

Whilst both parents and staff mention a plethora of teaching strategies, these are varied and lack detail. This is partially because of the struggle to conceptualise what progress looks like for a child with complex additional support needs. However it also suggests that both groups would benefit from further clarity about whether they should be using strategies which can be applied to a group of children with complex additional support needs (as suggested in the paragraph above) or whether, for some pupils, further focus should be placed on the development of strategies which are reflective of an individual child's strengths and difficulties and also their aetiology. This is consistent with an aetiology-specific approach (Oliver, Woodcock and Adams, 2010) and also with the 'individual differences' position debated by Norwich and Lewis (2001) which advocates the use of distinct teaching approaches to support the atypical progress of individual children with complex additional support needs.

The outcomes also suggest that a joint intervention – akin to that of the EYSCY group described in the study – can contribute to shared understandings of development between parents and other professionals. The programme was facilitated by a number of professionals on a rolling basis and provided the opportunity for parents to learn ways of increasing their child's engagement and to participate in dialogue about their child's development. In this informal setting, participants indicated that there was a dilution of the parent-professional power differential. This was empowering to parents and made it easier for them to ask for advice and to try out interactions and play in a safe setting. Yet the purpose of such a group needs to be further explored and refined, in addition to clarifying the intended outcomes for parents and children. Given the findings of this study, it will be beneficial to ensure that such a group provides a context for making different conceptualisations of development explicit. This will be further explored in the 'Implications for Practice' section of the Conclusion.

4.2 Methodological Considerations and Limitations

4.2.1 Sample

This evaluative study provides an example of real-life, school-based research (Robson and McCartan, 2016) with associated practical limitations which are explored below. Consideration was also given to the validity and reliability of qualitative research and the principles advocated by Eatough and Smith (2008), Guba and Lincoln (2005) and Yardley (2008) were espoused.

Although I had originally employed purposeful sampling as a means of ensuring that both the parents and nursery workers had experience of supporting an early year's child with complex

additional support needs, the final sample was restricted by the difficulty of recruiting enough suitable participants within one local authority. I had initially wished to interview the parents of young children between the ages of two and three years old. This decision was based on the fact that it was considered more appropriate to involve parents prior to their child's transition to school. However, this was not possible given that the population of early years children with complex additional support needs regularly accessing a nursery setting in the participating authority (South Lanarkshire) was very small. For example, two of the children whose families were contacted had complex health needs which meant that they were spending long periods in hospital throughout the course of the research. This meant that there was only one set of parents in the final sample, the mother and father of Ruby, whose child's needs could be considered more 'profound' and whose development was very much intertwined with the level of care she necessitated.

The children whose parents were selected as participants were identified based on information presented by heads of establishment of nursery and in discussion with educational psychologist colleagues. In the final sample, the interview information indicted that the needs of two of the children may not fit neatly with the descriptor 'complex additional support needs', as detailed in the Education Scotland 'Milestones' document (Education Scotland, 2019). One of the children with an autism diagnosis, Joe, was beginning to use some language functionally and demonstrating increased cognitive skills. Another child, Daisy, was beginning to demonstrate some increased signs of communication and non-verbal reasoning skills.

The fact that the sample was not representative of children with the most significant needs and that there were conflicting views amongst nursey staff about which children were appropriate to be included in the research highlights the fact that early years education staff may feel uncertain about determining those children who can be described as having 'complex additional support needs'. Yet, in another regard, the descriptor is deliberate in its vagueness; it takes into consideration the difficulty of defining the nature of a child's needs in the early years (as evidenced by the emerging skills of the two children referred to above). It also prevents an overreliance on more deficit-based labels which could be perceived by parents to be too deterministic or limiting at this early stage of a child's lives and which could adversely influence how they viewed their child's development.

The difficulties of employing a useful descriptor to both define and address a child's needs is also reflective of the contradictions that emerge from the data; whilst a descriptive label may help to determine how best to define these learners as a group, it fails to provide specific information about the support and strategies which best meet a child's needs within an educational setting. This

is evident in the rather vague accounts of the diverse strategies that are employed by parents and nursery staff to support the progress of a child. It also perhaps highlights the overall importance of adhering to an individualised approach and describing a child's needs based on an in-depth knowledge of their strengths, difficulties and motivators.

The fact that the nursery provided the main point of contact for the research resulted in all initial parent participants being mothers (with the exception of one father participant who attended the first part of the interview in lieu of his wife).Whilst two of the female participants indicated that their active involvement in their child's development was in contrast to their male partner's lack of involvement, the participating father's comments indicated his love for his daughter but his lack of active involvement or avoidance in addressing how her development may progress. There is only a small body of research about the fathers' views of children with disabilities. In studies conducted in the 1990s, the outcomes suggested that fathers were more likely to experience stress because of their child's presentation (Krauss, 1993), and to worry about their own degree of attachment or bonding with the child (Cohen, 1999; Krauss, 1993). Several other studies highlight fathers' concerns about their ability to support the family financially as a result of the child's needs (Cohen, 1999; Heaman, 1995). In this research study, further analysis or a more in-depth interview with the one participating father may have clarified whether his reluctance to learn more about his daughter's development was indicative of significant 'emotional labour' (Hochshild, 1983), and a lack of permission to talk about and discuss his feelings towards his daughter.

4.2.2 Methodology

Cohesion was maintained between the research design and the methodology used. The use of Interpretative Phenomenological Analysis (IPA) as a method of analysis was consistent with the study's social constructionist epistemology and based on the assumptions that reality and knowledge are constructed and subjective, rather than discovered independently from researchers (Smith, Flowers & Larkin, 2009). It also enabled me to reflect upon how my own experience of mothering a son with very complex additional support needs was a driver for the research and how both my personal and professional roles informed the analyses of data. I was aware that my role as an educational psychologist influenced how participants viewed the research situation and what information they shared during the interview and focus group.

The individual interviews employing open-ended questions were particularly appropriate given the sensitive nature of topic for parent participants; it enabled them to talk more openly about their experiences and to acknowledge the emotional impact of their child's development. Although my professional role could have had a negative influence on parents' willingness to contribute their

views, my existing and positive relationship with three of the parent participants, in addition to my training in and experience of active listening and therapeutic interviewing approaches, facilitated open discussion and encouraged participants to share their feelings and experiences. This made it easier for me to analyse the participant interviews and to make informed inferences about participants' views - even when these were not explicit. Semi-structured audio-recorded interviews also allowed for repeated revisiting of the data to check emerging themes and remain true to participants' accounts of their views of their child's development and their lived experiences.

The study also provided the opportunity to obtain the views of the small sample of parents and nursery staff at two distinct moments in time and in two different contexts. Thick and verbatim extracts were employed to capture individual views and to compare and contrast these with others. However, although the employment of another researcher to corroborate or indeed challenge main themes would have increased the study's validity, the sensitive and confidential nature of the content meant that this was considered inappropriate. The research took place within an educational context where both parents and education staff were influenced by existing and often inexplicit power differentials which could potentially prevent them for speaking openly. Indeed, the power differentials arising from these cultural norms were an overarching them to emerge from the data. For this reason, I made clear to all participants that I would be the sole researcher to have access to the recordings and transcripts.

To counter the lack of peer debriefing, all participants were invited to comment on the main research findings and to either confirm or challenge these in a focus group which took place between seven and eleven months after the initial interview. Not all original participants were able to attend; two of the nursery staff could not attend because of work commitments; one nursery worker had left her post since the initial interview whilst another was on annual leave. Two parents were also unable to attend because of medical appointments and one parent did not reply to the request. This suggests that in some instances, a second individual interview would have facilitated the participation of those participants who were more reluctant or unable to participate in the group setting.

In the focus group, all parent participants indicated that their views of their child's development had changed over time; they were able to provide examples of their child's strengths, even if these deviated from prevalent norms of child development. Yet, given the very small sample size and the use of qualitative research, it is unclear if these views are representative of all mothers or if the mothers participating in the research were more likely to have reflected on their child's development. It may be, too, that those parent participants whose views regarding their child's

development had not changed over time or who were struggling to notice progress, chose not to participate in the focus groups. This suggests the need to further explore ways of engaging parents with a wide range of views in research which is very sensitive in nature.

4.3 Implications for Practice

The findings of the study highlight the importance of adopting a broader ecological model of development as a means of better understanding and supporting the development of young children with complex additional support needs;- one which considers the way in which conceptualisations of development are constructed individually and relationally, and in different settings, and how these are simultaneously informed by wider cultural norms and existing power differentials. What emerges, therefore, is the need to support professional development experiences which enable early years staff to integrate the perspectives of parents, more contemporary theories of disability and ecological models of development into their understandings of this group of learners. The purpose of this is threefold:

(1) To allow staff to consider the socially constructed and contextualised nature of disability and to reconsider dominant narratives about children with complex additional support needs which inform educational policy and practice, and which reinforce existing power differentials.

(2) To equip early years staff and parents with a broader understanding of dominant theories of child development, as well as learning how the progress of children with complex additional support needs differs from that of their typically developing peers (Imray & Hinchcliffe, 2014). This would include a better understanding of how individual aetiologies may inform a child's cognitive profile, as well considering the extent to which a child's progress evolves as a result of their interaction and engagement with diverse environments and social practices.

(3) To explore ways of nursery staff working collaboratively with parents to facilitate a shared understanding of progress and to consider the implementation and evaluation of strategies which best promote their progress.

One of the aims of the professional Doctorate is to consider how the research findings can be applied to educational psychology practice. Since three of the core roles of an educational psychologist are to conduct assessment and provide training and consultation, (Scottish Government, 2002), they are well placed to provide the suggested support to both nursery staff and parents of young children with complex additional support needs. In addition, given their

knowledge of different models of development and the broader ecological model underpinning educational psychology practice, they are able to make different views explicit, whilst taking into consideration a child's aetiology. For example, training delivered by educational psychologists to nursery staff on the development of children with additional support needs can also include further discussion about the term inclusion. This may involve an exploration of the connotations and implications of different categorisations which are used in different settings to describe a child's needs. However, since the findings from implementation science research highlight the ineffectiveness of one-off training sessions (Blase, Fixsen, Naoom, & Wallace, 2005), consideration should be given to ways in which each of the three objectives above can be applied to practice. These are discussed below.

4.3.1 Using the Questionnaire in Practice

Given the implicit power differentials within the education system, (Sousa, 2015), consideration should be given to who should ask these questions and in what setting. Educational psychologists may be well placed to elicit this information with parents in the home setting, before asking the same questions to the key nursery worker in the nursery. This may facilitate the establishment of a positive and open working relationship between parents and nursery staff or highlight any conflicting views at the earliest stage of a child's education. This can then inform strategies which aim to reduce 'developmental incongruence' and also paves the way for implementing targets and strategies to promote a child's progress.

Whilst key questions are provided below, the full set of questions is provided in Appendix 3.

1.Tell me a bit about your/the child. What is he/she good at? (his/her strengths) What does he/she find more difficult?

2. What motivates him/her? What are his/her likes/dislikes? How do you know?

3. How does your/the child communicate his or her needs? (e.g. that he/she wants something/doesn't like something)

4. How would you compare your/the child's development and progress to that of other children?

5. What to you, are the most important aspects of your/the child's development? (E.g. what is a main focus for you? What is it important that he/she learns to do? Why?)

6. What practices/strategies do you use to try and encourage his or her development in these areas?

7. Can you describe any meaningful moments regarding your/the child's development and progress?

8. Has anyone or anything really influenced the way you think about your/the child's development? (E.g. really helped you to understand your/the child's development; or changed the way you think about their development?)

9. Do you share your/the views and beliefs about your/the child's development with the nursery/parents? And with other professionals? How have you shared your/the views? How do you find this?

10.What does progress look like for your/the child?

4.3.2 Employing the Linear Trajectory Meaningfully

The outcomes of the study also highlight that there is continual conflict between the wish for a child to adhere to the linear trajectory, whilst at the same time acknowledging difference. Indeed, rejecting dominant expert narratives and constructing new ones is not a quick easy or complete solution (Romme, Escher, Dillon et al., 2009). However, according to Becker (2007), those who are cognisant and accepting of this 'to- and fro-ing' between normalcy and difference are able to recreate a kind of 'new order'. For this reason, it is recognised that the dominance and importance of the linear trajectory of development should be made explicit and used as a gauge of progress in a way that is meaningful and sensitive to the needs of the individual child (particularly in the case of those children who follow this trajectory, albeit at a much slower pace). Therefore, it will be advantageous to adopt the linear trajectory as a baseline by explicitly describing how a child's development diverges from this line. Thus, it makes sense to describe progress as 'stop and start'; 'spikey, 'on and off' and 'plateauing.'

At the same time, consistent with this attempt to balance cultural norms with a child's individual needs, focus should be placed on identifying and celebrating atypical aspects of progress (e.g. how a child with complex additional support needs communicates by stilling or raising an arm; how a child with autism engages in play by spinning wheels). It will also be important to place emphasis on the relationship of the child's abilities to the features of the environment (e.g. demand on functional skills, physical features, attitudes, etc, akin to the aims of ICF-CY.) Consideration of how this framework can be applied in a Scottish setting will be included in Section 4.4.

4.3.3.Using Aetiology-Specific Research

Although the research outcomes highlight the complex nature of conceptualising development for this group of learners, and the influence of dominant norms and narratives, it does not dismiss nor discount biological based understandings of development. Indeed, as evidenced in the research, a child's diagnosis does not necessarily lead to a reductionist approach and all participants speak in positive terms about having a specific diagnosis as a means of obtaining a better understanding of their child. Instead, a diagnosis can contribute to further understanding of how a child makes progress, by highlighting likely areas of strength and weakness, and potentially informing approaches which can be used in the classroom to further promote progress. The findings therefore advocate using aetiology-specific research (Oliver, Woodcock & Adams, 2010) as a means of contributing to a better understanding of the child's learning needs. This will provide further understanding about the child's strengths and weaknesses consistent with the diagnosis. It will also reduce assessment time and inform strategies which use a child's motivators as a means of promoting his or her engagement and may help to facilitate parent-teacher dialogue about what constitutes progress for a child.

4.3.4 Developing a Joint Intervention

The literature also suggests further avenues for the creation of joint interventions for children with complex additional support needs, similar to that of the multi-agency EYSCY intervention, and facilitated by a number of professionals, including educational psychology. Two of the three approaches to intervention advocated by Sameroff and Fiese (2000), can be incorporated within the proposed intervention: redefinition (strategies directed towards more optimal interactions through an alteration in beliefs and behaviours) and re-education (teaching others how to respond to the child). This proposed intervention should place emphasis on establishing and discussing individual views about the child's development in this informal and supportive setting, whilst at the same time enabling parents and professionals to work together to identify a child's motivators and to promote his or her development. In accordance with the tenets of the phenomenological approach to research advocated by Simmons (2018), this would enable those supporting a child to share insights and interpretations from observations over a long period of time and to develop richer understandings of what constitutes progress for a child. Such a group would also provide the opportunity for parents to talk to other parents who have children with a similar level of need. Indeed, the outcome of this research and other studies suggests that such groups may incur a sense of belonging which is not possible in other parent-child groups (Dawson & Burner, 2011). It also provides the opportunity for parents to support one another.

The intervention can also be extended to involve nursery staff – namely the keyworkers of the participating children. The aim, therefore, would be to support parents and nursery staff in establishing the motives underlying their behaviours and noticing and celebrating atypical examples of progress. The overall aim would be for parents and nursery staff to obtain a clearer conceptualisation of development for a child and to align parents' and staff beliefs about the child's progress, and to ensure that their responses and strategies are based on an in-depth understanding of the child's strengths, difficulties and motivators.

4.4 Areas for Future Research

The research findings indicate that educational psychologists, trained in both therapeutic approaches and research methodology, are in a good position to conduct qualitative research that is sensitive in nature. Yet, although research is one of the five core functions of educational psychologists in Scotland (Scottish Government, 2002), quantitative research methods are often prioritised at an authority and national level as a means of establishing the outcomes and effectiveness of educational policy and practice. Qualitative methods are used less often or alongside quantitative data as a means of triangulating findings. However,, in this study, the use of purely qualitative data led to richer and more in-depth accounts from participants and was judged to be a more appropriate way of gaining further information from a population about which less is known.

Qualitative methodology is also consistent with the social constructionist epistemology which informs educational psychology practice, and which emphasises the importance of considering different perspectives and of evaluating the roles and experiences of individuals within different multi-agency contexts. This suggests that there is a further need to explore ways in which qualitative methodologies can be employed more frequently – and also pragmatically - in real-world educational settings as a means of gaining a further understanding of pupils' and teachers' individual experiences of supporting children with additional support needs. This will be especially useful when trying to obtain the views of smaller and less-researched populations. Further areas for future research are explored below.

The fact that the nursery provided the main point of contact for the research resulted in all initial parent participants being mothers (with the exception of one father participant who attended the first part of the interview in lieu of his wife). Whilst two of the female participants indicated that their active involvement in their child's development was in contrast to their male partner's lack of involvement, the participating father's comments indicated his love for his daughter but his avoidance of addressing how her development may progress. There is a small body of less recent

research about fathers' views of children with disabilities, which suggests that fathers are more likely to experience stress because of their child's presentation (Krauss, 1993; McBride, Schoppe & Rane (2002). Further research may also help to clarify whether fathers' roles and their potential reluctance to discuss their child's development, are indicative of significant 'emotional labour' (Hochschild, 1983) and a lack of permission to talk openly about their feelings about their child's development. How does this contribute to or indeed diminish their status as a father? Further research should also compare mothers' views with those of fathers to establish the extent to which cultural factors such as current gender norms inform parental conceptualisations of development and responses to a child.

In the focus group, all parent participants indicated that their views of their child's development had changed over time; they were able to provide examples of their child's strengths, even if these deviated from prevalent norms of child development. It would be beneficial to conduct a longitudinal study involving the same parents to ascertain how their views of their child's progress change over time and in response to different educational environments and practices. It would also be advantageous to conduct a similar qualitative study with parents of school aged children with complex additional support needs to elicit their views of their child's progress, and to ascertain how and if their conceptualisations of progress change as a result of the age of the child, their stage of schooling and in response to the input from different education staff.

The research proposed above requires further implementation and evaluation of the study's questionnaire in order to establish its effectiveness in facilitating more open discussion between parents and staff about a child's development. This will also help to discern instances where there is little or no power differential between parents and nursery staff and whether this in turn leads to a shared understanding of a child's development. For those parents who more easily abandon these cultural norms, is this facilitated by an equal relationship with professionals? It would also be helpful to discover which factors - at a cultural, social, and relational level - inform the views of parents and professionals who adhere to a linear trajectory, even when a child consistently fails to adhere to developmental norms. Would further dialogue at an earlier stage and throughout a child's schooling help to reduce this incongruence and also reduce existing power differentials?

The outcomes of the study could then be used to further refine the aims of the joint intervention and evaluate its impact. For example, it may be possible to establish whether such an intervention leads to a change in parental views about their child's development and also increased insightfulness between both parties when talking about how they view a child's progress. Since initial research suggests that increased insightfulness improves the attachment relationship between

parents and a child with learning difficulties (Feniger-Schaal, Oppenheim, Koren-Karie and Yirmiya, 2012), the longer-term outcome of the joint intervention would be to evaluate the impact of the intervention on both views of development and more fundamentally, on parents' attachment with their child. This is especially important, given the literature highlighting feelings of 'diminished motherhood' reported by mothers of children who fail to adhere to societal norms of development (Landsman, 2005).

The proposed joint intervention may also provide a context to explore the relationship between parental beliefs about development and the responses they employ to facilitate interaction – and if these change as a result of the intervention. Research has found that it can be difficult to determine the direct relationship between parents' beliefs about their child's development and the responses that they employ to promote this (Sigel, 1992). Since self-report measures lack reliability, the intervention may provide the opportunity to observe the behaviours and strategies that adults employ during parent-child interaction. It would also be advantageous to explore nursery-staff and child interaction, and to compare this with nursery staff beliefs, and also with parent beliefs. This will necessitate consideration of an appropriate methodology since observational coding is not always reliable when observing the atypical behaviours of children with complex additional support needs (Sigel, 1992). The adoption of a more participatory approach, as advocated by Simmons (2018), would correspond with a social-constructionist epistemology. This could include the use of 'vignettes', observational field-notes of adult-child's interactions within a particular environment. These could then be then critiqued by other adults supporting the child to triangulate the information obtained and to inform a more multi-faceted approach to understanding how beliefs inform the strategies used by parents and nursery staff.

The outcomes of this study also highlight the importance of education staff feeling that they have both knowledge of and permission to use assessment and teaching approaches which take into account and celebrate the individual trajectories of children with complex additional support needs. The initial evaluative research on the ICF-CY in educational settings suggests the value of making revisions to the classification system to enable its application to a Scottish context. This may involve the potential development of an assessment tool (Norwich 2016; Hollenweger, 2014) which would maintain the integrated approach to understanding a child's needs, by combining knowledge of their aetiology, alongside an understanding of their functioning and participation in different settings.

The development of such a tool would also require clarification of how the different components of the ICF-CY can be operationalised so that they can be applied in a Scottish educational context

and used in current educational psychology practice. For example, the broad coverage of the ICF-CY 'activity' and 'participation' components over nine areas means that each specific area does not cover the relevant detail from an educational perspective (Norwich, 2016). There should also be further thought given to how other concepts such as 'wellbeing', not evident in the current ICF-CY but an integral part of the Scottish curriculum, can be operationalised for this group of learners and included in such an assessment tool. It would then be beneficial to explore how such a tool could be used with both parents and education staff so that areas where there are differences in views can be made explicit at the assessment stage. Perhaps this requires further development of the questionnaires used as part of Project II. This would potentially provide a much more integrated model of assessment which would accord with both a biopsychosocial approach and cultural historical model of assessment and intervention.

Further research should include the implementation and evaluation of aetiology-specific teaching strategies as recommended by Oliver, Woodcock and Adams (2010) and more in-depth evaluation of current strategies being employed by teachers and parents. Indeed, further evaluation is needed to clarify whether effective teaching strategies are akin to those which support the development of a typically developing population, or whether distinct and specifically developed strategies for this group of learners (e.g. Intensive Interaction) in addition to aetiology-specific strategies (e.g. TEACCH approach for children with autism; Mesibov, Shea, & Schopler, 2005) are a more effective means of promoting the meaningful progress of a child with complex additional support needs. Indeed, the current dearth of evaluative research into effective teaching strategies for this group of learners is partially attributable to the uncertainty about what constitutes progress for an individual child. Perhaps the adoption of a more integrated and ecological model of understanding and assessing the needs of children with complex additional support needs, as advocated by the outcomes of this research study, will result in more confident conceptualisations of progress. This can them inform more comprehensive assessment and teaching approaches which focus on the child, and the impact of different environments on their functioning and participation.

4.5 Conclusion

The analysis of the data in this study leads to a deeper understanding of the experiences and views of parents and nursery staff who are actively supporting the development of a child with complex additional support needs. The use of Interpretative Phenomenological Analysis (IPA) enabled an exploration of views of development within a specific socio-cultural context at a point in time and led to further reflection upon the role played by cultural factors in informing these views - both at a micro level (the level of the individual, family and nursery) and macro level (the level of

educational policy etc.). Consistent with the assumptions of social constructionism, the study indicates that the outcomes of a child with complex additional support needs and how progress is viewed may be the product of interactions at these different levels (e.g. at the level of the child-parent, child- nursery staff, nursery staff-parent; curriculum-nursery staff-child.)

Ultimately, the research study advocates a broader, more integrated and more culturally informed understanding of the development of children with complex additional support needs which aims to minimise power differentials between parents and education staff. This includes consideration of a child's aetiology, but also the extent to which perspectives of a child's progress are informed by cultural, social and relational factors. In the longer term, it is anticipated that this approach can be applied to wider educational psychology practice when discussing the categorisations used in education and when addressing a mismatch between parents' and professionals' understanding of a child's development. It is also hoped that the outcomes of the research can inform further discussion about the use of teaching approaches which include an in-depth understanding of an individual child, consideration of the environments which promote their engagement and a recognition of how both parents and nursey staff can accept and celebrate progress that is considered out with the norm. Significantly, this necessitates involvement not only from staff and parents, but from those involved in curriculum planning for children with complex additional support needs

4.6 Concluding Comments

This thesis set out to out to explore understandings of progress for children with complex additional support needs and how these can inform teaching and learning approaches and educational psychology practice. What began as an attempt to build capacity amongst educational staff and facilitate an understanding of a child's individual needs, broadened in scope and depth to include the views of parents and explore the influence of environmental factors and dominant cultural discourses on conceptualisations of development for young children with complex additional support needs. The structure of the thesis is also reflective of my increasingly confident espousal of a social constructionist epistemology which enabled me to obtain rich accounts of parent and nursery staff participants. The analysis of this qualitative data suggests that parents' and education staff views about progress and the factors that influence these should be made explicit and that the teaching of young children with complex additional support needs should be based on a shared understanding of what constitutes progress for a child.. Throughout the process, I have been mindful that the motivation for the thesis is also driven by my own lived experience as a mother to a young son with cerebral palsy and my struggle both to understand and promote his progress.

4.6.1. The Overall Process

The process – the RPL claim, the literature review, and Project II are summarised below:

The RPL claim provides an example of my involvement at an authority level to build capacity amongst education staff in understanding the development of this group of learners. The South Lanarkshire Framework for supporting pupils with complex additional support needs ('The Framework') (Appendix 2.1), and the article which details its implementation, and evaluation (Rees, Tully and Ferguson, 2017)(Appendix 2.2), promulgates the identification of relevant and individualised learning outcomes and evidence-based teaching approaches which promote pupils' development in key areas. The results also highlighted a continuing need to clarify definitions of 'progress' for this group of learners. What was lacking were the perspectives of parents and how they could and should be co-producers of educational plans for their children. This provided the rationale or the thesis.

The literature review provided further analysis of both parents' and teachers' views of progress and how parent-child interaction and teacher responses are informed by pedagogy, policy and prevalent models of disability. However, there was an evident dearth of research comparing the views of both populations. The resulting research, Project II, provided an opportunity to do this using both individual interviews and focus groups. Despite there being five initial research questions, the

participants' responses indicated that cultural norms of development, embedded in everyday discourse, informed individual and educational responses to children with complex additional support needs and continued to reinforce negative power differentials.

The outcomes of the analysis of data suggested that participants' conceptualisations of development and the emotional impact on parents vary according to the extent to which they adhere to the linear trajectory. Indeed, views oscillated between embracing cultural norms and rejecting them (described metaphorically by one parent as 'throwing away the red book' in which health visitors track predicted milestones of progress). Further analysis, especially of the focus group data, indicated that it is often only with the passing of time, and with an increased knowledge of the child, that parents and nursery staff participants were able to identify aspects of progress which necessitate conceptualising the development of a child with complex additional support needs as deviating from the linear trajectory. One parent participant described this as her 'new norm'. Those participants who celebrated atypical examples of progress or who could understand the motives behind the child's behaviour gave more specific accounts of progress. The extent to which the term 'insightfulness' can be applied to this group of parents has yet to be further explored but the outcomes of Project II suggest that a child's progress is dependent upon how it is defined and upon there being a shared sense of what constitutes meaningful development. Thus, definitions of a child's progress are socially constructed through dominant narratives of development, and through interactions with a child.

The research validates my adherence to social constructionism – not only at an ideological level but at a practical level too. The findings also endorse the ecological model of development underpinning educational psychology practice and highlight the importance of placing further emphasis on wider cultural norms. The Conclusion section of Project II advocates enabling early years staff to integrate the perspectives of parents and ecological models of development into their understandings of this group of learners by adopting an integrated approach to assessing and addressing a child's development. This is consistent with the cultural-historical model proposed by the (Bøttcher & Dammeyer, 2016) but also draws from other theoretical positions. For example, it takes into account how aetiological research can be used to inform teaching approaches which identify individual and meaningful aspects of development. A joint intervention is also proposed which involves both parents and nursery staff in working towards shared views of progress in an informal and non-judgemental setting. It is hypothesised that shared views of development will lead to more specific examples of progress being noted and celebrated.

A number of years down the line, the process in which I have engaged in completing the Doctorate has enabled me to make better sense of my experience as a mother and to comprehend the factors which contributed to my own conceptualisations of my son's development. Significantly, this thesis has helped me to better understand - and indeed accept- my son's development in a way that was not possible during his life. It is hoped that the outcomes of the research will inform educational psychology practice and shape the experience of other parents and educational staff so that the development of children with complex additional support needs is better understood and their progress celebrated. Ultimately, this will require more explicit discussion about cultural norms, and about the interpretation and application of the term inclusion. This perhaps requires a fundamental shift in thinking about how we define progress for all children.

REFERENCES

Abbeduto, L., Warren, S. F., & Conners, F. A. (2007). Language development in Down syndrome: From the prelinguistic period to the acquisition of literacy. Mental retardation and developmental disabilities research reviews, 13(3), 247-261.

ACSET (1984). (Advisory Committee on the Supply and Education of Teachers) Teacher Training and Special Educational Needs.

Aldrich, R. (1988). *The National Curriculum: an historical perspective*. The National Curriculum, 21-33.

Als, H., Gilkerson, L., Duffy, F. H., Mcanulty, G. B., Buehler, D. M., Vandenberg, K. & Butler, S.C. (2003). A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting, and caregiving effects. *Journal of Developmental & Behavioral Pediatrics, 24*(6), 399-408.

Atkinson, L., Scott, R, Chisholm, V., Blackwell, J., Dickens, *S.,* Tarn, E, & Goldberg, S. (1995). Mothers of children with Down syndrome. Cognitive coping, affective distress band maternal sensitivity *Developmental Psychology, 31, 668-676*.

Avramidis, E., Bayliss, P., & Burden, R. (2000). Student teachers' attitudes towards the inclusion of children with special educational needs in the ordinary school. Teaching and teacher education, 16(3), 277-293.

Avramidis, E., & Norwich, B. (2002). Teachers' attitudes towards integration/inclusion: a review of the literature. *European Journal of Special Needs Education*, *17*(2), 129-147.

Ball, R. S. (1977). The Gesell Developmental Schedules: Arnold Gesell (1880–1961). *Journal of abnormal child psychology, 5*(3), 233-239.

Bang, J. (2009). An environmental affordance perspective on the study of development – artefacts, social others, and self. In M. Hedegaard, M. Fleer & J. Tudge (Eds.), *World yearbook of education* (pp. 160–178). New York: Routledge.

Barber M. (2008) Using intensive interaction to add to the palette of interactive possibilities in teacher-pupil communication. *European Journal of Special Needs Education 23*, 393–402.

Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants & Young Children*, *16*(3), 184-200.

Battaglia, A., & Carey, J. C. (2003). Diagnostic evaluation of developmental delay/mental retardation: An overview. In American Journal of Medical Genetics Part C: Seminars in Medical Genetics (Vol. 117, No. 1, pp. 3-14). New York: Wiley Subscription Services, Inc.

Becker, G. (1997). Disrupted lives: How people create meaning in a chaotic world. Univ of California Press.

Berger, P. L., & Luckmann, T. (1966). T.(1966). The social construction of reality. *Operationalizing implementation: Strategies and methods*. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute.

Bobath, B. (1975). Sensorimotor development. *American NDT Newsletter*, *7*, 1.

Booth, T., Ainscow, M., Black-Hawkins, K., Vaughan, M., & Shaw, L. (2000). *Index for inclusion: Developing learning and participation in schools*. CSIE, Bristol: England.

Bornstein, M. H., & Tamis-Lemonda, C. S. (1997). Maternal responsiveness and infant mental abilities: Specific predictive relations. *Infant Behavior and Development*, *20*(3), 283-296.

Bøttcher, L. (2014). Transition between home and school in children with severe disabilities—Parents' possibilities for influencing their children's learning environment. *Learning, Culture and Social Interaction*, *3*(3), 195-201.

Bøttcher, L., & Dammeyer, J. (2016). Development and Learning of Young Children with Disabilities: A Vygotskian Perspective (Vol. 13). Switzerland: Springer.

Bronfenbrenner, U. (1994). Ecological models of human development. *Readings on the development of children, 2*(1), 37-43.

Bronfenbrenner, U., and Evans, G. W. (2000). Developmental science in the 21st century: emerging questions, theoretical models, research designs and empirical findings. *Soc. Dev. 9*, 115–125. doi:10.1111/1467-9507.00114

Bronfenbrenner, U., & Morris, P. A. (1998). The ecology of developmental processes.

Broomhead, K. E. (2013). 'You cannot learn this from a book'; pre-service teachers developing empathy towards parents of children with Special Educational Needs (SEN) via parent stories. *European Journal of Special Needs Education, 28*(2), 173-186.

Bruce , S., & Muhammad, Z. (2009). The development of object permanence in children with intellectual disability, physical disability, autism, and blindness. *International Journal of Disability, Development and Education*, *56*(3), 229-246.

Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F. J., ... & Tyrer, F. (2012). Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric.

Bruner, J. (1984). *Vygotsky's zone of proximal development: The hidden agenda. New Directions for Child Development.*

Buckley, S., & Bird, G. (1993). Teaching children with Down syndrome to read. *Down syndrome Research and practice, 1*(1), 34-39.

Burack, J.A., Hodapp, R.M., Iarocci, G. & Zigler, E. (2012). On knowing more: future issues for developmental approaches to understanding persons with intellectual disabilities. In J.A. Burack, & R.M. Hodapp, R. M. (Eds.). (2012). *The Oxford handbook of intellectual disability and development.* Oxford Library of Psychology.

Burr, V. (2015). *Social constructionism.* Routledge. London/

Cacioppo, J. T. (2002). Social Neuroscience: Understanding the Pieces Fosters Understanding the Whole and Vice Versa, *American Psychologist*, 57(11), 819-831.

Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development*, *15*(3), 275-282.

Capps, L., Kehres, J., & Sigman, M. (1998). Conversational abilities among children with autism and children with developmental delays. *Autism*, *2*(4), 325-344.

Carey (2014) Taming the Tiger Parent: How to put your child's well-being first in a competitive world . Robinson: London.

Carpenter, B., Egerton, J., Brooks, T., Cockbill, B., Fotheringham, J., Bloom, T. & Thistlethwaite, J. (2015). *Engaging Learners with Complex Learning Difficulties and Disabilities: A resource book for teachers and teaching assistants*. England: Routledge.

Castro, S., Pinto, A., and Simeonsson, R. J. (2014). Content analysis of Portuguese individualized education programmes for young children with autism using the ICF-CY framework. *European Early Child. Educational. Research, 22*(1).

Chandler, D. (2002*). Semiotics: The basics*. London: Routledge

Chapman, R. S., Kay-Raining Bird, E., Burack, J., Hodapp, R., Iarocci, G., & Zigler, E. (2012). Language development in childhood, adolescence, and young adulthood in persons with Down syndrome. *The Oxford handbook of intellectual disability and development*, 167-183.

Cicchetti, D. & Beeghly, M. (1990). *Children with Down Syndrome: A Developmental Perspective.* Cambridge: Cambridge University Press.

Cielinski, K. L., Vaughn, B. E., Seifer, R., & Contreras, J. (1995). Relations among sustained engagement during play, quality of play, and mother-child interaction in samples of children with Down syndrome and normally developing toddlers. *Infant Behavior and Development*, *18*(2), 163-176.

Coburn, D. (1992). Freidson then and now: An "internalist" critique of Freidson's past and present views of the medical profession. *International Journal of Health Services*, *22*(3), 497-512.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of health and social behavior,* 51(1_suppl), 67-79.

Cook, B. G. (2001). A comparison of teachers' attitudes toward their included students with mild and severe disabilities. *The journal of special education*, *34*(4), 203-213.

Coster, W.J., Law, M.C., and Bedell, G.M. (2010). *Participation and Environment Measure for Children and Youth (PEM-CY)*. Boston, MA: Boston University

Council for Curriculum, Examinations & Assessment (CCEA) (2009). *Quest for Learning.* Guidance & Assessment Materials Profound & Multiple Learning Difficulties. Belfast: CCEA.

Coupe O'Kane, J., & Goldbart, J. (1998).*Communication before speech: Development and assessment*. London: David Fulton.

Crawley, S. B., & Spiker, D. (1983). Mother-child interactions involving two-year-olds with Down syndrome: A look at individual differences. *Child development*, 1312-1323.

Dammeyer, J. (2010). Parents' management of the development of their children with disabilities: Incongruence between psychological development and culture. *Outlines. Critical Practice Studies*, *12*(1), 42-55.

Dawson, G., & Burner, K. (2011). Behavioral interventions in children and adolescents with autism spectrum disorder: a review of recent findings. *Current opinion in pediatrics*, *23*(6), 616-620.

De Geeter, K. I., Poppes, P., & Vlaskamp, C. (2002). Parents as experts: the position of parents of children with profound multiple disabilities. *Child: care, health and development, 28*(6), 443-453.

Dempsey, I., & Dunst, C. J. (2004). Help giving styles and parent empowerment in families with a young child with a disability. *Journal of Intellectual and Developmental Disability*, *29*(1), 40-51.

Dempsey, I., Foreman, P., Sharma, N., Khanna, D., & Arora, P. (2001). Correlates of parental empowerment in families with a member with a disability in Australia and India. *Developmental Disabilities Bulletin*, *29*(2), 113-131.

DES. (1978). Warnock Committee Report. London: HMSO.

Dewson, M. R., & Whiteley, J. H. (1987). Sensory reinforcement of head turning with nonambulatory, profoundly mentally retarded persons. *Research in Developmental Disabilities*, *8*(3), 413-426.

Diau, D. (2017) The real shape of progress. In I.Wallace, and L.Kirkman (Eds).' Progress.'p48. Camarthen, Wales: Crownhouse Publishing Limited.

Donnellan, A. M. (1984). The criterion of the least dangerous assumption. *Behavioral Disorders, 9(*2), 141-150.

Doran, P. (2012). *The Right Help at the Right Time at the Right Place: Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs*, The Scottish Government. Online at http://www.gov.scot/Resource/0040/00408307.pdf (Accessed 16th September 2016).

Dunst, C. J., & Dempsey, I. (2007). Family–professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education*, *54*(3), 305318.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta- analysis of family- centered helpgiving practices research. Mental retardation and developmental disabilities research reviews, 13(4), 370-378.

Dykens, E.M., Hodapp, R.M. & Leckman, J.F. (1994). *Behavior and Development in Fragile X Syndrome*. Thousand Oaks, CA: Sage Publications. I.

Eatough, V., & Smith, J. A. (2008). *Interpretative phenomenological analysis*. The Sage handbook of qualitative research in psychology, 179, 194.

Edley, N. (2001). Unravelling social constructionism. *Theory & Psychology,* 11(3), 433-441.

Education Scotland (2019) *Milestones; Supporting Learners with Complex Additional Support Needs.*

Elder-Vass, D. (2012). Towards a realist social constructionism. Sociologia, problemas e práticas, (70), 9-24.

Farrell, M. (2004). *Inclusion at the crossroads***.** London: David Fulton.

Farrell, P., Dyson, A., Polat, F., Hutcheson, G., & Gallannaugh, F. (2007). The relationship between inclusion and academic achievement in English mainstream schools. *School Effectiveness and School Improvement*, *18*(3), 335-352.

Feniger-Schaal, R., & Oppenheim, D. (2013). Resolution of the diagnosis and maternal sensitivity among mothers of children with intellectual disability. *Research in developmental disabilities*, *34*(1), 306313.

Feniger-Schaal, R.,Oppenheim, D., Koren-Karie, N., & Yirmiya, N. (2012). Parenting and intellectual disability: An attachment perspective. In. J.A. Burack, R.M. Hodapp, G.Iarocci, and E.Zigler (Eds.). *The Oxford handbook of intellectual disability and development.* (pp. 334-348). New York: Oxford University Press.

Fisher, P., & Goodley, D. (2007). The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of health & illness*, *29*(1), 66-81.

Flewitt, R., & Nind, M. (2007). Parents choosing to combine special and inclusive early years settings: the best of both worlds?. *European Journal of Special Needs Education*, 22(4), 425-441.

Florian, L. (2008). Inclusion: special or inclusive education: future trends. *British Journal of Special Education, 35*(4), 202-208.

Florian, L., & Black-Hawkins, K. (2011). Exploring inclusive pedagogy. *British Educational Research Journal, 37*(5), 813-828.

Florian, L., & McLaughlin, M. J. (2008). *Disability classification in education: Issues and perspectives.* Corwin Press.

Foreman, P., Arthur-Kelly, M., Pascoe, S., & King, B. S. (2004). Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom settings: An Australian perspective. *Research and Practice for Persons with Severe Disabilities*, *29*(3), 183-193.

Forlin, C. (1995). 'Educators' beliefs about inclusive practices in Western Australia', *British Journal of Special Education, 22,* 179–185

Forness, S. R., & Kavale, K. A. (1994). The Balkanization of special education: Proliferation of categories for" new" behavioral disorders. *Education and Treatment of Children,* 215-227.

Foucault, M. (2019). Power: the essential works of Michel Foucault 1954-1984. Penguin UK.

Friedson, E. (1970). *Profession of Medicine: A Study of the Sociology of Applied Knowledge.* New York: Harper and Row.

Garrison, J. (1998). Toward a pragmatic social constructivism. Constructivism and education (1998): 43-60.;- In. Larochelle, Bednarz, Garrison, & Garrison, (Eds.). *Constructivism and education.* Cambridge University Press.

Gillies, R. M., & Carrington, S. (2004). Inclusion: Culture, policy and practice: A Queensland perspective. (2), 117-128.

Gillham, B. (Ed.). (1978). *Reconstructing educational psychology.* Taylor & Francis.

Glenn, C. V. (2018). *The Measurement of Teacher's Beliefs About Ability: Development of the Beliefs About Learning and Teaching Questionnaire*. Exceptionality Education International, 28(3).

Glenn, C.V. (2007). *The impact of teachers' epistemological beliefs and their beliefs about disability on their teaching practices in inclusive classrooms*. Unpublished PH.D. dissertation, University of Toronto.

Goddard, J., Lehr, R., & Lapadat, J. (2000). Constructivist counselling and parents of children with disabilities. *Canadian Journal of Counselling*, *34*(4), 154-171.

Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Goodnow, J. J., & Collins, W. A. (1990). *Development according to parents: The nature, sources, and consequences of parents' ideas*. Psychology Press.

Gorman-Smith D, Beidel D, Brown T.A, Lochman J., & Haaga A.F.(2003). Effects of teacher training and consultation on teacher behavior towards students at high risk for aggression. *Behavior Therapy;34*:437–452.

Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child care, health and development, 3*3(3), 296-307.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (p. 191–215). Sage Publications Ltd.

Guess, D., Siegel-Causey, E., Roberts, S., Guy, B., Ault, M. M., & Rues, J. (1993). Analysis of state organizational patterns among students with profound disabilities. *Journal of the Association for Persons with Severe handicaps*, *18*(2), 93-108.

Guralnick, M. J. (Ed.). (2005). *The developmental systems approach to early intervention*. Baltimore: Paul H Brookes Publishing Company.

Harris, S., Kasari, C., & Sigman, M. D. (1996). Joint attention and language gains in children with Down syndrome. *American journal of mental retardation: AJMR*, *100*(6), 608-619.

Haskins, R., & Loeb, S. (2007). *A plan to improve the quality of teaching in American schools*. Brookings Institution.

Hed, G. L. (1992). Anniversaries—the biopsychosocial complementarity of keeping count and not keeping count. *Psychosomatic medicine,* 54(5), 543-545.

Hedegaard, M. (2009). Children's development from a cultural–historical approach: Children's activity in everyday local settings as foundation for their development. *Mind, Culture, and Activity, 16*(1), 64-82. Hobbs, V. (2009). Maximising the progress of learners with profound and multiple learning difficulties, The SLD Experience, 55(1) 1

Hochschild, A.R. (1983). *The managed heart: commercialization of feeling*. Berkeley: University of California Press.

Hodapp, R. M., & Zigler, E. (1997). New issues in the developmental approach to mental retardation. *Ellis' handbook of mental deficiency, psychological theory and research*, *3*, 115-136.0-16.

Hollenweger, J. (2014). Definition and Classification of Disability. New York: UNICEF http://www.inclusiveeducation.org/sites/default/files/uploads/booklets/IE_Webinar_Booklet_2.pdf accessed 10th October, 2019.

Hooper, H., & Walker, M. (2002). Makaton peer tutoring evaluation: 10 years on. *British Journal of Learning Disabilities, 30(*1), 38-42.

Hornby, G.(1994). *Counselling in Child Disability: Skills for Working with Parents*. London: Chapman and Hall

Hutchinson, N., & Bodicoat, A. (2015). The effectiveness of intensive interaction, a systematic literature review. *Journal of Applied Research in Intellectual Disabilities*, *28*(6), 437-454.

Ibragimova, N., Granlund, M., and Bjorck-Akesson, E. (2009). Field trial of ICF version for children and youth (ICF-CY) in Sweden: logical coherence, developmental issues and clinical use. *Developmental Neurorehabilitation*. 12, 3–11. doi:10.1080/17518420902777001

Imray, P. & Hinchcliffe, V. (2014). *Curricula for Teaching Children with Severe or Profound and Multiple Learning Difficulties.* Abingdon: Routledge.

Janus, M., Kopechanski, L., Cameron, R., & Hughes, D. (2008). In transition: Experiences of parents of children with special needs at school entry. *Early Childhood Education Journal*, *35*(5), 479485.

Jones K. & Howley M. (2010). An investigation into an interaction programme for children on the autism spectrum: outcomes for children, perceptions of schools and a model for training. *Journal of Research in Special Educational Needs* 10, 115–123.

Jones, P. (2002). *Making meaning with teachers of pupils with profound and multiple learning difficulties: reflecting on identity and knowledge*. Doctoral thesis, Northumbria University.

Jordan, A., Glenn, C., & McGhie-Richmond, D. (2010). The Supporting Effective Teaching (SET) project: The relationship of inclusive teaching practices to teachers' beliefs about disability and ability, and about their roles as teachers. *Teaching and teacher education*, *26*(2), 259-266.

Keenan, M., Kerr, K. P., & Dillenburger, K. (2000). *Parents' education as autism therapists: applied behaviour analysis in context*. London: Jessica Kingsley Publishers.

Kellett, M. (2003). Jacob's journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the intensive interaction teaching approach. *Journal of Research in Special Educational Needs 3*, 1–16.

Kellett, M. (2004). Intensive interaction in the inclusive classroom: using interactive pedagogy to connect with students who are hardest to reach. *Westminster Studies in Education 27*, 175–188.

Kellett, M. (2005) Catherine's legacy: social communication development for individuals with profound learning difficulties and fragile life expectancies. *British Journal of Special Education 32,* 116–121.

Kellett, M., & Nind, M. (2013). *Implementing intensive interaction in schools: Guidance for practitioners, managers and co-ordinators*. Routledge.

Leadbetter, J., Kelly, B., Woolfson, L., & Boyle, J. (2008). Activity theory and the professional practice of educational psychology. *Frameworks for practice in educational psychology: A textbook for trainees and practitioners,* Jessica Kingsley: London.

Kirp, D.L. (1982). Professionalization as a policy choice; British special education in comparative perspective. *World Politics, 34*(2), 137-174.

Kratochvil, M. S., & Devereux, S.A. (1988). Counseling needs of parents of handicapped children. *Social Casework,* 68,420-426.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American journal on mental retardation.*

Kübler-Ross, E. (1969). *On death and dying.* New York: Scribner's.

Kuczynski, L., & Parkin, C. M. (2009). Pursuing a dialectical perspective on transaction: A social relational theory of micro family processes. In A. Sameroff, A. (Ed). *The transactional model.* (pp247268). New York: American Psychological Association.

Lacey, P. (2011). Developing a Curriculum for Pupils with PMLD, *The SLD Experience, 61*(1), 4-7.

Lalvani, P. (2015). Disability, stigma and otherness: perspectives of parents and teachers. *International Journal of Disability, Development and Education, 62*(4), 379-393.

Landry, S. H., Garner, P. W., Swank, P. R., & Baldwin, C. D. (1996). Effects of maternal scaffolding during joint toy play with preterm and full-term infants. *Merrill-Palmer Quarterly* (1982-), 177-199.

Landry, S. H., & Loveland, K. A. (1988). Communication behaviors in autism and developmental language delay. *Journal of Child Psychology and Psychiatry, 29*(5), 621-634.

Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities, 26*(2), 121139.

Lawson, H., Waite, S. & Robertson, C. (2005). Distinctiveness of Curriculum Provision at 14 to 16 for Students with Learning Difficulties: Opportunities and Challenges, *British Journal of Special Education*, *32*(1), 12-20.

Lebeer, J., & Rijke, R. (2003). Ecology of development in children with brain impairment. *Child: care, health and development, 29*(2), 131-140.

Lewis, A., & Norwich, B. (2004). *Special teaching for special children? Pedagogies for inclusion: A pedagogy for inclusion?*. McGraw-Hill Education (UK).

Hollellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society, 15*(1), 157–165.

Lerner, R. M., & Castellino, D. R. (2002). Contemporary developmental theory and adolescence: Developmental systems and applied developmental science. *Journal of Adolescent Health*, *31*(6), 122135.

Lewis, A., & Norwich, B. (2005). *Special Teaching For Special Children*? *Pedagogies For Inclusion.* McGraw-Hill Education. Berkshire: Open University Press.

Llewellyn & K. Hogan (2000) The Use and Abuse of Models of Disability, *Disability & Society, 15*:1, 157-165

Lieberman, D., Paden-Belkin, E., & Harel, S. (1995). Maternal directiveness and infant compliance at one year of age: A comparison between mothers and their developmentally delayed infants and mothers and their nondelayed infants. *Journal of Child Psychology and Psychiatry*, *36*, 1091-1096.

Lindsay, G. (2007). Educational Psychology and the Effectiveness of Inclusive Education/Mainstreaming, *British Journal of Educational Psychology,* 77(1), 1-24.

Lindsay, G., & Dockrell, J. E. (2004). Whose job is it? Parents' concerns about the needs of their children with language problems. *The Journal of Special Education, 37(*4), 225-235.

Lindsay, G., Dockrell, J., Law, J., & Roulstone, S. (2012). *Better communication research programme: Improving provision for children and young people with speech, language and communication needs*. London: DfE.

Low, C. (1997) Is inclusivism possible? *European Journal of Special Needs Education, 12* (1), 71–79

Mahoney, G., & Robenalt, K. (1986). A comparison of conversational patterns between mothers and their Down syndrome and normal infants. *Journal of Early Intervention*, *10*(2), 172-180.

Marfo, K., Dedrick, C., & Barbour, N. (1998). Mother-child interactions and the development of children with mental retardation. 637.

Marvin, R. S., & Pianta, R. C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology*, *25*(4), 436-445.

Maxwell, G.R., Granlund, M., & Augustine, L. (2018.) *Inclusion Through Participation: Understanding Participation in the International Classification of Functioning, Disability, and Health as a Methodological Research Tool for Investigating Inclusion*. Frontiers in Education, 3(41).

McBrien, J. & Foxen, T. (1981). *Training Staff in Behavioural Methods: The EDY In-service Course for Mental Handicap Practitioners: Instructor's handbook*. Manchester: Manchester University Press

McBride, B. A., Schoppe, S. J., & Rane, T. R. (2002). Child characteristics, parenting stress, and parental involvement: Fathers versus mothers. *Journal of Marriage and Family*, *64*(4), 998-1011.

McClimens, A. (2005). From Vagabonds to Victorian Values: The Social Construction of a Disability Identity. In G. Grant, P. Goward, M. Richardson & Ramcharan, P. (Eds.) *Learning Disability: A Life Cycle Approach to Valuing People*, (pp. 28-46). Berkshire: Open University Press

McDermott, R., & Varenne, H. (1995). Culture as disability. Anthropology & Education Quarterly, 26(3), 324-348.

Mesibov, G. B., Shea, V., & Schopler, E. (2005*). The TEACCH approach to autism spectrum disorders*. New York: Springer Science & Business Media.

Meyer, E. C., Coll, C. T. G., Seifer, R., Ramos, A., Kilis, E., & Oh, W. (1995). Psychological distress in mothers of preterm infants. *Journal of Developmental & Behavioral Pediatrics*, *16*(6), 412-417.

Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the diagnosis among parents of children with autism spectrum disorder: Associations with child and parent characteristics. *Journal of autism and developmental disorders*, *40*(1), 89-99.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Reprint—preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Physical therapy, 89*(9), 873-880.

Moretti, M., Alves, I., and Maxwell, G. (2012). A systematic literature review of the situation of the International Classification of Functioning, Disability, and Health and the International Classification of Functioning, Disability, and Health–Children and Youth version in education: a useful tool or a flight of fancy? *American. Journal of Physical and Medical Rehabilitation (91*), 103–117.

Mortimer, H. (1995). Welcoming young children with special needs into mainstream education. *F*(4), 164-169.

Munde, V. S., Vlaskamp, C., Ruijssenaars, A. J. J. M., & Nakken, H. (2009). Alertness in individuals with profound intellectual and multiple disabilities: A literature review. *Research in Developmental Disabilities*, *30*(3), 462-480.

Nind, M. (1996). Efficacy of intensive interaction: developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction. *European Journal of Special Needs Education 11*, 48–66.

Nind, M., & Hewett, D. (2012). *Access to communication: Developing the basics of communication with people with severe learning difficulties through intensive interaction*. London: Routledge

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. Evidence-based nursing, 18(2), 34-35.

Norwich, B. (2002). Education, Inclusion and Individual Differences: Recognising and Resolving Dilemmas*, British Journal of Educational Studies, 50(4*), 482-502.

Norwich, B. (2016) Conceptualizing Special Educational Needs Using a Biopsychosocial Model in England: The Prospects and Challenges of Using the International Classification of Functioning Framework. Front. Educ. 1:5.doi: 10.3389/feduc.2016.00005

Norwich, B. & Lewis, A. (2001). Mapping a Pedagogy for Special Educational Needs, *British Educational Research Journal*, 27(3), 313-329.

O'Brien G. (2002). The clinical relevance of behavioural phenotypes. In: G O'Brien (Ed.) *Behavioural Phenotypes in Clinical Practice.* (pp. 1–12.).London: MacKeith Press.

O'Brien, Y., Glenn, S., & Cunningham, C. (1994). Contingency awareness in infants and children with severe and profound learning disabilities. *International Journal of Disability, Development and Education*, *41*(3), 231-243.

Odom, S. L., & Diamond, K. E. (1998). Inclusion of young children with special needs in early childhood education: The research base. *Early Childhood Research Quarterly, 13(*1), 3-25.

Oliver, C., Woodcock., K. A. & Adams, D. (2010). The importance of aetiology of intellectual disability. *Learning Disability A life Cycle Approach*, Second Edition. (pp. 135-146). McGraw Hill, Berkshire: Open University Press.

Olswang, L. B., Pinder, G. L., & Hanson, R. A. (2006,). Communication in young children with motor impairments: Teaching caregivers to teach. In *Seminars in Speech and Language* (Vol. 27, No. 03, pp. 199-214). New York: Thieme Medical Publishers, Inc.

Oppenheim, D., & Koren-Karie, N. (2002). Mothers' insightfulness regarding their children's internal worlds: The capacity underlying secure child–mother relationships. *Infant mental health journal*, *23*(6), 593-605.

Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between maternal insightfulness/resolution and child–mother attachment: The case of children with Autism Spectrum Disorder. Attachment & human development, 14(6), 567-584.

Paine, R. S. (1962). On the treatment of cerebral palsy. The outcome of 177 patients, 74 totally untreated. *Pediatrics*,*1,* 605–616.

Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology, 7*(2), 99-121.

Piaget, J. (1964). Part I: Cognitive Development in Children: Piaget, Development and Learning, *Journal of Research in Science Teaching.*

Porter, J. (2005). Awareness of number in children with complex additional support needs: three exploratory case studies. *British Journal of Learning Disabilities, 33*(3), 97-101.

Read, J. (1992). *Conductive Education, 1987-1992: The Transitional Years*. Foundation for Conductive

Reid, D. K., & Weatherly Valle, J. (2004). The Discursive Practice of Learning Disability: Implications for Instruction and Parent—School Relations. *Journal of Learning Disabilities, 37(*6), 466-481.

Rees, K (2016). *The South Lanarkshire Framework for supporting children with severe and profound leaning needs, Proceedings of the 41stScottish Educational Research Association Conference,* University of Dundee, Scotland.

Rees, K., Tully, S., & Ferguson, K. (2017). "This is theirs": The implementation of the South Lanarkshire Framework for supporting pupils with complex additional support needs. *Educational Review, 49(*1), 67-88.

Riddell, S (2008) The Classification of pupils at the educational margins in Scotland: Shifting Categories and Frameworks in L. Florian, and M.J. McLauglin (Eds) *Disability Classification in Education.* Corwin Press: CA.

Roach, M. A., Barratt, M. S., Miller, J. F., & Leavitt, L. A. (1998). The structure of mother–child play: Young children with Down syndrome and typically developing children. *Developmental Psychology*, *34*(1), 77.

Robson, C., & McCartan, K. (2016). Real world research. John Wiley & Sons.

Romme, M., Escher, S., Dillon, J. et al. (2009). Living with voices: 50 stories of recovery. Ross-on-Wye: PCCS Books.

Roskam, I., & Schelstraete, M. A. (2007). A qualitative analysis of mothers' childrearing behaviour towards their disabled child. *Research in Developmental Disabilities*, *28*(2), 130-144.

Sameroff, A. In Sameroff, Arnold (Ed). (2009). *The transactional model of development: How children and contexts shape each other,* (pp. 3-21). Washington, DC, US: American Psychological Association.

Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J.P. Shonkoff,., & S.J. Meisels, (Eds).(pp.135-159). *Handbook of early childhood intervention.* Cambridge: Cambridge University Press.

Scottish Executive Education Department. (1999). Implementing inclusiveness, realising potential (The Beattie Report). Edinburgh: HMSO.

Scottish Executive Education Department. (2000). Standards in Scotland's Schools, etc. Act. Edinburgh: HMSO.

Scottish Government (2002) 'The Currie Report: Review of Provision of Educational Psychology Services in Scotland. Edinburgh: Scottish Government. https://www2.gov.scot/resource/doc/158375/0042905.pdf.; accessed 29th May 2017.

Scottish Government (2009). The Curriculum for Excellence. Edinburgh; Scottish Government. Available at: www.educationscotland.gov.uk/Images/all-experinces-outcomes-tem4-539562.pdf, accessed 24th July 2016 .

Selman, R.L. (1971). The Relation of Role-Taking Ability to the Development of Moral Judgement in Children, *Child Development,* 42, 79-91.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader,* 2, 197-204

Sigel, I.E. (1992) In I.E. Sigel, A.V. McGillicuddy-DeLisi, J.G.Goodnow. (1992).(Eds.) *Parental Belief Systems: The Psychological Consequences for Children* (Second Edition). Hillsdale, NJ: Lawrence Erlbaum Associates.

Simmons, B. (2018). *The PMLD ambiguity: articulating the life-worlds of children with profound and multiple learning disabilities*. Routledge.

Simmons, B & Watson, D. (2015). From Individualism to Co-construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities, *Child Care in Practice, 21:*1, 50-66.

Smail, D. (2005). Power, interest and psychology: *Elements of a social materialist understanding of distress.*

Ross-on-Wye: PCCS Books. Smart, C.

Smith, J.A. 1996 Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*: 261–271

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method, and research*. London: Sage

South Lanarkshire Inclusion Service and Psychological Service (2015). *The South Lanarkshire Framework for supporting pupils with complex additional support needs*. South Lanarkshire: South Lanarkshire Council.

Sousa, A. C. (2015). "Crying Doesn't Work": Emotion and Parental Involvement of WorkingClass Mothers Raising Children with Developmental Disabilities. *Disability Studies Quarterly, 35*(1).

Spiker, D., Boyce, G. C., & Boyce, L. K. (2002). Parent-child interactions when young children have disabilities. *International review of research in mental retardation*, *25*, 35-70.

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities, 20*(1), 39-51.

Tamis- LeMonda, C. S., Way, N., Hughes, D., Yoshikawa, H., Kalman, R. K., & Niwa, E. Y. (2008). Parents' goals for children: The dynamic coexistence of individualism and collectivism in cultures and individuals. *Social development, 17*(1), 183-209.

The Bridge School (2013). *Curriculum for Pupils with Complex additional support needs.* Online at http://www.thebridgelondon.co.uk/assets/filemanager/downloads/The%20Bridge%20PMLD%20Curriculum%202013.pdf (Accessed 16/9/16).

Travers, J., & Ayres, K. M. (2015). A critique of presuming competence of learners with autism or other developmental disabilities. *Education and Training in Autism and Developmental Disabilities, 5*0(4), 371.

Trevarthen, C. (1979). Communication and cooperation in early infancy: A description of primary intersubjectivity. *Before speech: The beginning of interpersonal communication*, *1*, 530-571.

Trevarthen, C., & Aitken, K. J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Journal of child psychology and psychiatry*, *42*(1), 3-48.

Tulkin, S. R., & Cohler, B. J. (1973). Childrearing attitudes and mother-child interaction in the first year of life. *Merrill-Palmer Quarterly of Behavior and Development*, *19*(2), 95-106.

Vale of Evesham School (2014). *Vale of Evesham School Profound and Multiple Learning Difficulties Curriculum*. Retrieved online at: http://valeofeveshamschool.org/Links/curriculum/pmld%20curriculum/vale%20of%20Evesham%2PMLD%20Curriculum.pdf (Accessed 16/9/16).

Van Walwyk, L. (2011). Measuring progress in children with profound and multiple learning difficulties. *The SLD Experience*, *60*(1), 9-16.

Von Tetzchner, S., Verdel, M., Barstad, B. G., Gravås, E. M. H., Jahnsen, R., Krabbe, S., & Bang, B. (2013). The effect of interventions based on the programs of The Institutes for the Achievement of Human Potential and Family Hope Center. *Developmental neurorehabilitation*, *16*(4), 217-229.

Vygotsky, L. S. (1993). The diagnostics of development and the pedological clinic for difficult children. *The collected works of LS Vygotsky: The fundamentals of defectology (abnormal psychology and learning disabilities)*, *2*, 241-291.

Waite, J., Heald, M., Wilde, L., Woodcock, K., Welham, A., Adams, D. & Oliver, C. (2014). The

Importance of Understanding the Behavioural Phenotypes of Genetic Syndromes Associated with Intellectual Disability, *Paediatrics and Child Health*, 24(10), 468-472.

Ware, J. (2003). *Creating a responsive environment for people with profound and multiple learning difficulties* (2nd ed.). London: David Fulton

Ware, J. (2012). *Creating a responsive environment for people with profound and multiple learning difficulties*. London: Routledge.

Wehmeyer, M. L., Shogren, K. A., Palmer, S. B., Williams-Diehm, K. L., Little, T. D., & Boulton, A. (2012). The impact of the self-determined learning model of instruction on student selfdetermination. *Exceptional Children, 78(*2), 135-153.

Weisz, J. R., & Yeates, K. O. (1981). Cognitive development in retarded and nonretarded persons: Piagetian tests of the similar structure hypothesis. *Psychological Bulletin, 90*(1), 153.

Welsh Assembly Government (WAG) (2006). *Routes for Learning Additional Guidance: Assessment Materials for Learners with Profound Learning Difficulties and Disabilities.* Retrieved from: http://learning.gov.wales/docs/learningwales/publications/121115routeslearningadditionalen.pdf (Accessed 16/9/16).

Werner, H., & Strauss, A. (1939). Problems and methods of functional analysis in mentally deficient children. *The Journal of Abnormal and Social Psychology, 34*(1), 37.

White, R. (2007) *Characteristics of classroom teachers which contribute to their professional growth in implementing their inclusive classroom practices*. Unpublished MA thesis, University of Toronto.

Woolfson, L & Brady, K. (2009). An investigation of factors impacting on mainstream teachers' beliefs about teaching students with learning difficulties, *Educational Psychology, 29*(2), 221-238.

World Health Organization. (2001). International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization.

World Health Organization. (2007). International Classification of Functioning, Disability, and Health – Children and Youth. Geneva: World Health Organization.

Willig, C (2012). *Qualitative interpretation and analysis in psychology*. McGraw-Hill Education (UK).

Worden, J. W. (2008). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer Publishing Company.

Yando, R., Seitz, V., & Zigler, E. (1989). Imitation, recall, and imitativeness in children with low intelligence of organic and familial etiology. *Research in developmental disabilities*, *10*(4), 383-397.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.

Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood–insights from families with disabled children in Norway. *Disability & Society, 23*(6), 625-636.

Zigler, N. (1967). Familial mental retardation: A continuing dilemma. *Science, 20*(3760), 292-298.

Ziolko, M. E. (1991). Counseling parents of children with disabilities: A review of the literature and implications for practice. *Journal of Rehabilitation*, *57*(2), 29.

APPENDICES

APPENDIX 1. Definition of Complex Additional Support Needs

(South Lanarkshire Inclusion Service and Psychological Service (2015, p6).

Complex additional support needs

Children and young people with complex additional support needs may have more than one disability, the most significant of which are complex additional support needs. They are likely to experience difficulties problem solving, playing co-operatively and forming relationships. Some pupils may use signs and/or symbols to communicate whilst others may use some language although this may not always be functional. Children and young people with complex additional support needs will require on-going support for most if not all aspects of daily life. They may also have:

- sensory and physical disabilities
- on-going health needs such as epilepsy

This level of disability may also exist comorbidly with other disabilities and disorders such as Autism, Down's syndrome, or other chromosomal disorders

Complex additional support needs

Children and young people with complex additional support needs are likely to have more than one disability, but their most significant area of need is in relation to their learning disability. They are likely to experience difficulty learning to communicate, eat, reach out and actively engage with others. These pupils are mostly non-verbal and may sometimes use eye pointing, vocalisations and gestures to communicate. Some may also use alternative augmentative communication aids. They require high levels of support with all aspects of daily life such as intimate care, feeding and clothing (South Lanarkshire Inclusion Service and Psychological Service (2015, p5).

They will also have:

- additional sensory and physical disabilities
- multiple, complex and on-going health needs such as severe epilepsy, a gastrostomy or a tracheostomy
- a physical disability such as cerebral palsy, spina-bifida or hydrocephalus

APPENDIX 2. Project 1

APPENDIX 2.1 RPL Claim

(1). 'The South Lanarkshire Framework for supporting pupils with complex additional support needs' (South Lanarkshire Council, 2015).

(2)Implementation and Evaluation of the of Framework

References

APPENDIX 2.2

Presentation of the evaluation at the SERA (Scottish Educational Research Association) conference, November 2016.

APPENDIX 2.3

Journal Article: "This is theirs": The implementation of the South Lanarkshire Framework for supporting pupils with complex additional support needs (Rees, K., Tully, R., and Ferguson, S. (2017).
Scottish Educational Review, v49 n1 p67-88 2017).

APPENDIX 2.1 RIPL CLAIM

May 2017

SQF Level 12 Prior Learning

This RPIL claim is based on work which I have already produced at doctorate level. This includes a substantial policy document (1), for which I was the lead author. The second piece of work (2.1), an article detailing the implementation and evaluation of the aforementioned document, was published in a peer reviewed journal. This is supplemented by a paper (2.2) which was presented at the Scottish Educational Research Association (SERA) conference in November 2016.

(1). 'The South Lanarkshire Framework for supporting pupils with complex additional support needs' (South Lanarkshire Council, 2015). http://www.southlanarkshire.gov.uk/downloads/file/9818/framework_for_supporting_pupils_with_severe_and_profound_learning_needs

(2.1) Rees, K., Tully, R., and Ferguson, S. (2017). "This is theirs": The implementation of the South Lanarkshire Framework for supporting pupils with complex additional support needs (Scottish Educational Review, v49 n1 p67-88 2017).
https://www.researchgate.net/publication/322303348_This_is_theirs_The_implementation_of_the_South_Lanarkshire_Framework_for_supporting_pupils_with_severe_and_profound_needs

(2.2) Presentation of the evaluation at the SERA (Scottish Educational Research Association) conference, November 2016.

The claim is for 20% of the award.

(1) The South Lanarkshire Framework for supporting pupils with complex additional support needs

The South Lanarkshire Framework for supporting pupils with complex additional support needs ("The Framework") was developed as a result of both a local needs analysis (an evaluation of the curriculum for pupils in an Additional Support High School, plus consultation with staff in this sector) and national priorities (The Doran Review: *'The Right Help at the Right Time at the Right Place'*, Doran, 2012; The Curriculum for Excellence, Scottish Government, 2009). I facilitated an authority working party which led to its development. The document assists Scottish schools in

taking forward the Curriculum for Excellence for this group of learners and in building capacity amongst staff. The guidance and resources place emphasis on the identification of relevant and individualised learning outcomes and on evidence-based teaching approaches which promote pupils' development in key areas.

The contents are detailed below. I wrote those sections marked with an asterisk, after collaboration and discussion with members of the working party.

*** 1. Introduction**

2. Definitions of Complex additional support needs

3. The Curriculum for Excellence and Key Areas

4. Assessment, Monitoring and Target Setting

*** 5. Approaches to Teaching and Learning**

*** 6. Health and Well-Being and Addressing Challenging Behaviours**

*** 7. References**

*** 8. Useful Links**

*** 9. Appendices**

*** 10. Resources**

(2.1) Evaluation of the South Lanarkshire Framework for supporting pupils with complex additional support needs

This paper details the development, implementation and evaluation of the South Lanarkshire Framework for supporting children with complex additional support needs ("The Framework"). Seven ASN establishments in South Lanarkshire completed a pre- and post- audit of curricular practice and twenty-four staff completed an evaluative questionnaire. Eight staff also participated in semi-structured interviews. Analyses highlighted the positive impact of the Framework on teacher practice (clearer and more consistent curriculum planning; assessment and teaching approaches) and mind-set (increased confidence, understanding and reduced feelings of isolation). Significantly, participants suggested that the Framework had provided a clearer way of setting targets that was based on an assessment of a pupil's learning needs, rather than on common conceptions of development which assume a linear trajectory. Responses also suggested that the document had led to increased collaboration amongst staff and had been shared positively with parents. The results also highlighted a need to clarify definitions of 'progress' for this group of learners. The findings are discussed in relation to implications for practice and future research

Characteristic 1 Knowledge and Understanding

SCQF Level 12 Outcomes:

Demonstrate and/or work with:

• A critical overview of a subject/discipline, including critical understanding of the principal theories, principles and concepts.

• A critical, detailed and often leading knowledge and understanding at the forefront of one or more specialisms.

• Knowledge and understanding that is generated through personal research or equivalent work that makes a significant contribution to the development of the subject/discipline.

Evidence

I obtained a critical overview of the teaching, learning and development of children with complex additional support needs by conducting an informal literature search, the findings of which informed the contents of the Framework. This focused on 2 areas:

- The development of children with complex additional support needs, including an analysis of research involving children who demonstrate delayed development areas in all areas, in addition

to aetiology-specific research which highlights the cognitive profiles of children who belong to smaller homogenous groups.

- The curriculum and teaching approaches for children with complex additional support needs, including an analysis of curricular models over time, in addition to an analysis of specific teaching and assessment approaches developed with this group of learners in mind. This literature search resulted in an in-depth understanding of the principal theories, principles and concepts of the development of this group of leaners, including the 'The 2-Structure Model of Development', initially proposed by Zigler (1967). It also highlighted the influence of conflicting models of disability (e.g. medical model, social model) in different settings (medical settings; educational settings). The analysis also suggested that dominant developmental theories - assumptions of 'age and stage' theories of development - continue to inform curricular models, despite research which demonstrates very distinct learning trajectories for children with this level of cognitive impairment.

The review of the literature highlighted that fact that approaches to teaching this group of learners are informed more by current pedagogy, and by the prevalent policy of 'inclusion' than they are by research. The researcher made a significant contribution to the development of the subject since it informed the development of an authority-wide document to inform educational practice based on a more in-depth understanding of the development of this group of learners. Education Scotland was also consulted as part of the process, and the document has since been adopted and used by a number of authorities throughout Scotland.

Characteristic 2: Practice: Applied Knowledge, Skills and Understanding

SQF Level 12 Outcomes:

Apply knowledge, skills and understanding:

- **In using a significant range of the principal professional skills, techniques, practices and/or materials associated with the subject/discipline/sector.**
- **In using and enhancing a range of complex skills, techniques, practices and/or materials that are at the forefront of one or more specialisms.**
- **In applying a range of standard and specialised research and/or equivalent instruments and techniques of enquiry.**
- **In designing and executing research, investigative or development projects to deal with new problems and issues.**
- **In demonstrating originality and creativity in the development and application of new knowledge, understanding and practices.**

• To practise in the context of new problems and circumstances.

Evidence

I conducted the work in a challenging context; schools were keen to adhere to the Curriculum for Excellence yet had reported that they were finding it difficult to ensure that it was both meaningful and relevant for this group of learners.

The development of the Framework and its implementation and evaluation required me to use a range of complex skills, techniques, practices and materials at the forefront of Educational Psychology. These included:

- Consulting and collaborating with Additional Support Needs (ASN) establishments, key people in Education, educational psychologists and Education Scotland.
- Reflecting on the different perspectives informed by different professional ideologies (e.g. teachers were influenced by the curriculum; psychologists were influenced by developmental research.)
- Making these perspectives explicit and working towards a shared understanding, whilst ensuring that outcomes and the contents of the Framework were underpinned by a clear evidence base.
- Conducting a needs analysis (both the evaluation of a curriculum for this group of learners and obtaining the views from staff in ASN schools).
- Assimilating key information from research.
- Ensuring the application of this information to educational practice through the Framework. I demonstrated originality and creativity in the development and application of new knowledge, understanding and practices. The areas of the Curriculum for Excellence were presented in a diagram to highlight the focus on a narrower range of key areas for this group of learners (Communication; Cognition; Self-Care and Independence; Physical Skills). In the resource section of the document, I wrote a section containing banks of targets from identified key areas of the curriculum for this group of learners. This was informed by relevant assessment tools for learners with learning difficulties who do not follow a linear trajectory of development. (E.g. the Vineland Adaptive Behaviour Scales, Sparrow, Cicchetti, and Saulnier, 2016; Routes for Learning, WAG, 2006).

I developed step-by-step guides for teachers so that they could use these to conduct an assessment of challenging behaviours, and to ensure that the use of certain teaching tools (objects of reference;

visuals) were reflective of a child's cognitive ability. These were both creative but also pragmatic in the sense that they could be easily applied in the classroom.

(2) The Implementation of the South Lanarkshire Framework – Research and Evaluation

I was central to the planning of the implementation of the Framework, whilst being solely responsible for the planning of the document's evaluation. The implementation was based on key findings from implementation science, including the involvement of key stakeholders and an initial needs analysis.

I designed and implemented an appropriate and feasible research methodology. This was based on the fact that the evaluation was an example of 'real world' research, conducted in a school setting and subject to extraneous factors such staffing changes. Quantitative research methods (pre and post audit of curricular practice; questionnaire) were triangulated with qualitative data (interviews). This increased validity, given the small sample size and the fact that the evaluation was conducted within a school setting. Data was collected and analysed in a timeous and costeffective way.

Characteristic 3. Generic Cognitive Skills SQF

Level 12 Outcomes:

- **Apply a constant and integrated approach to critical analysis, evaluation and synthesis of new and complex ideas, information and issues.**
- **Identify, conceptualise and offer original and creative insights into new, complex and abstract ideas, information and issues.**
- **Develop creative and original responses to problems and issues.**
- **Deal with very complex and/or new issues and make informed judgements in the absence of complete or consistent data/information.**

Evidence

I applied a constant and integrated approach to the analysis of the data. Interviews were audio recorded and then transcribed verbatim before analysis commenced. Thematic analysis, influenced by Grounded Theory (Glaser and Strauss, 1967), was used in order to elicit and analyse themes and sub-themes from the data. The researcher used an inductive approach to avoid fitting themes into any preconceptions. Transcripts were read and re-read during the process of analysis and comments were initially coded through conceptual labels. The interconnections between concepts were explored and then divided into themes and transferred onto a grid, with relevant extracts

from the transcripts. The researcher met with the two research assistants on several occasions to provide further evidence of themes that had been extrapolated.

I developed an audit of curricular practice to provide an original self-evaluation tool for staff working with children with complex additional support needs. This focused on different aspects of the curriculum (Creating a Responsive Environment; Communication; Approaches to Teaching and Learning) and was based on research in each area of the audit. It required staff to complete a Likert scale as a means of evaluating their own practice in this area.

The shortcomings of the qualitative data were recognised (small sample size; staff changes in participating schools etc.). I therefore made an informed judgement by triangulating findings with themes which emerged from the semi-structured interviews. There are very few studies which aim to obtain the views of teachers working in this sector and the analysis of this data offered insight into the influence of both the Framework and the Curriculum for Excellence on teacher practice. This analysis also provided some original responses to current curricular practice by highlighting the need to clarify a definition of 'progress' for this group of learners and by emphasising the need to involve parents more actively in the process.

Characteristic 4. Communication, ICT and Numeracy Skills SQF

Level 12 Outcomes:

Use a significant range of advanced and specialised skills as appropriate to a subject/discipline, for example:

- **Communicate at an appropriate level to a range of audiences and adapt communication to the context and purpose.**
- **Communicate at the standard of published academic work and/or critical dialogue and review with peers and experts in other specialisms.**
- **Use a range of software to support and enhance work at this level and specify software requirements to enhance work.**
- **Critically evaluate numerical and graphical data.**

Evidence

I employed a range of advanced and specialised skills in order to inform appropriate audiences of the contents and application of the Framework and to disseminate the findings of the evaluation.

Prior to its publication, I disseminated a draft copy of the Framework for consultation to education staff in South Lanarkshire, Education Scotland, and to key partner agencies and organisations (e.g. PAMIS; SENSE).

The contents of the Framework and its evaluation were disseminated within the authority and I presented nationally at conferences and a national launch. The information was tailored to the specific audience and context. This enabled critical dialogue with educational psychology peers, education staff and other relevant agencies. These occasions are detailed below:

- A national launch of the document in South Lanarkshire at which I presented the aims and contents to a national audience (August 2015).
- A workshop at the Scottish Division of Educational Psychology National Conference detailing its contents and practical application for both educational psychologists and education staff (September 2015).
- A presentation at the Scottish Educational Research Association (SERA) Conference, detailing the outcome of the evaluation (November 2016).

An article detailing the implementation and evaluation of the Framework has been accepted by the Scottish Educational review and has now undergone final proofreading. It will be published in the forthcoming edition entitled: 'Diversity, Equity and Education in Scotland.'

I critically evaluated numerical and graphical data, in conjunction with the two research assistants. The SPSS programme was used to perform t-tests on the data obtained from the audits of curricular practice. As part of the evaluation, both quantitative and qualitative data were analysed and then presented using diagrams and graphs.

Characteristic 5. Autonomy, Accountability and Working with Others

Level 12 Outcomes:

- **Exercise a high level of autonomy and initiative in professional and equivalent activities.**

• Take full responsibility for own work and/or significant responsibility for the work of others.

• Demonstrate leadership and/or originality in tackling and solving problems and issues. in ways which are reflective, self-critical and based on research/evidence.

• Deal with complex ethical and professional issues.

• Make informed judgements on new and emerging issues not addressed by current professional and/or ethical codes or practices.

Evidence

- I demonstrated leadership and exercised a high level of autonomy and initiative by instigating, facilitating and chairing the authority working party, which led to the creation of the Framework.
- I worked hard to ensure that members from the Education Inclusion Service, Psychological Service and schools contributed to discussion. Throughout the process, I emphasised the importance of evidence-based practice.
- Throughout the process, I referred to relevant and sometimes conflicting literature and consulted with Psychological Service colleagues. As part of the working party aims, all members were charged with reading relevant research and taking time to discuss this during meetings.
- As the lead author and chair of the working party, it was necessary to make more complex decisions which arose because of the conflicting ideologies of those involved in the working party. This required further debate and discussion and necessitated a return to the literature to ensure that recommended practice was based on relevant research. It also informed further discussion about different conceptualisations of progress for this group of learners. This then suggested avenues for future research.
- I demonstrated autonomy and initiative. The implementation of the Framework adhered to implementation science (for example, it involved key stakeholders throughout the process to facilitate its implementation to practice). The evaluation was carefully planned, and I adhered to a strict timeline. I also managed the involvement of 2 research assistants and clarified their roles. For example, during the analysis of data, I met with 2 research assistants regularly to discuss outcomes and ensure validity.

The following authors have agreed that their contribution to the paper: "*This is theirs": The implementation of the South Lanarkshire Framework for supporting pupils with complex additional support needs'* was collectively 20 %.

Scott Tully/ Kirstin Ferguson

References

Doran, P. (2012). *The Right Help at the Right Time at the Right Place: Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs.* The Scottish Government. Online at http://www.gov.scot/Resource/0040/00408307.pdf (Accessed 16th September 2016).

Glaser, B. G. & Strauss, A.L. (1967) *The Discovery of Grounded Theory,* Chicago: Aldine. Scottish Government (2009). *The Curriculum for Excellence.* Edinburgh; Scottish Government. Available at: www.educationscotland.gov.uk/Images/all-experinces-outcomes-tem4-539562.pdf, accessed 24th July 2016.

Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2016). *Vineland-3: Vineland Adaptive Behavior Scales*. PsychCorp.

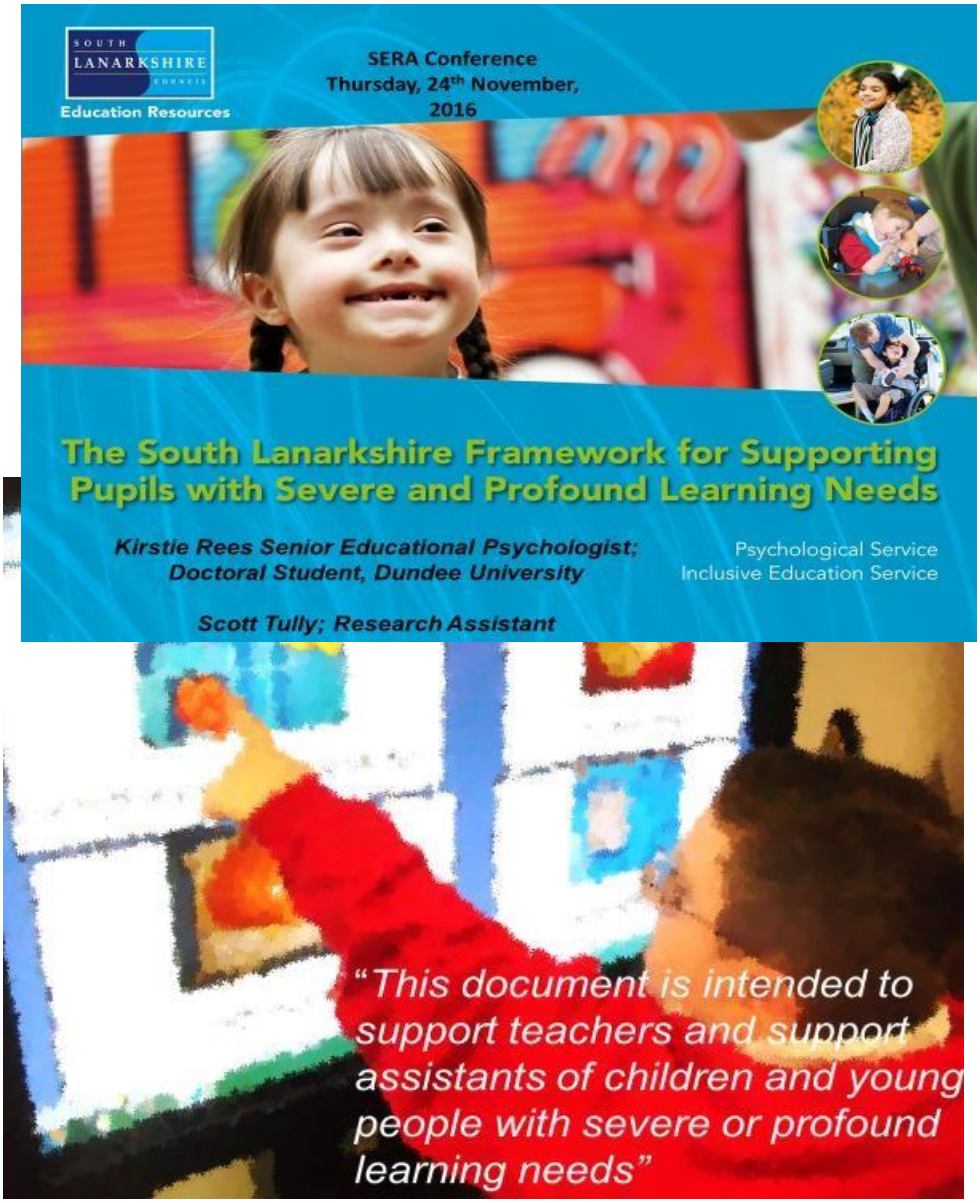
Rees, Kirstie, Scott Tully, and Kirstin Ferguson. "" This Is Theirs": The Implementation of the South Lanarkshire Framework for Supporting Pupils with Complex additional support needs." Scottish Educational Review 49.1 (2017): 67-88.

South Lanarkshire Inclusion Service and Psychological Service (2015). *The South Lanarkshire Framework for supporting pupils with complex additional support needs*. South Lanarkshire: South Lanarkshire Council.

Welsh Assembly Government (WAG) (2006). Routes for Learning Additional Guidance: Assessment Materials for Learners with Profound Learning Difficulties and Disabilities. Retrieved from: http://learning.gov.wales/docs/learningwales/publications/121115routeslearningadditionalen.pdf (Accessed 16/9/16).

Zigler, N. (1967). Familial mental retardation: A continuing dilemma. *Science, 20*(3760),

APPENDIX 2.2. Presentation of the evaluation at the SERA (Scottish Educational Research Association) conference, 2016.



The National Context

- The Doran Review
- The Curriculum for Excellence
- GIRFEC

Background

- Local Needs Analysis
- Working Party
- Consultation
- Implementation
- Evaluation

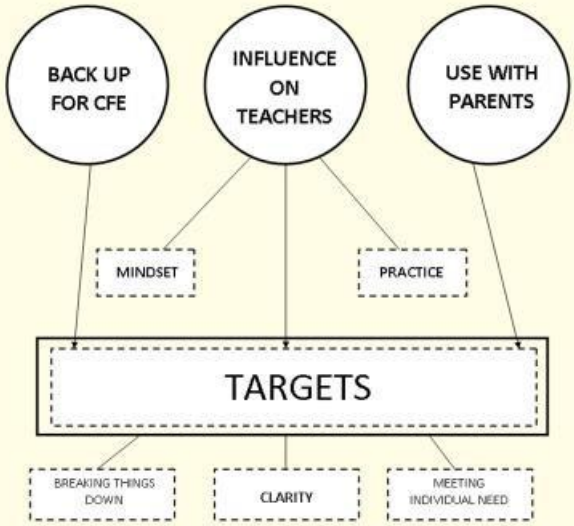

Developmental Basis
Based on Research
Practical
The Framework...
Curriculum for Excellence


Curriculum for Excellence
Social studies
Religious and moral education
Expressive Arts
Technologies
Sciences
English
Mathematics
Numeracy
Health and wellbeing
Cognition
Physical skills
Literacy
Communication
Self-care and independence
Child at the centre

Evaluation: Audit

Measure	Pre-test mean (SD)	Post-test mean (SD)	t	p
Creating a responsive learning environment	3.4 (0.36)	3.75 (0.19)	2.45	.058
Approaches to teaching and learning	2.80 (0.58)	3.44 (0.45)	5.97	.002**
Communication	3.33 (0.22)	3.68 (0.23)	7.01	.001**
Assessment, monitoring and target setting	3.07 (0.33)	3.64 (0.28)	3.22	.013*
Health and well-being and assessing and addressing challenging behaviours	3.1 (0.62)	3.73 (0.41)	3.95	.011*

Evaluation: Interviews



Next Steps

- Further evaluation of pupil progress
- Parental views /Teacher views

APPENDIX 2.3. Journal Article

The Implementation of the South Lanarkshire Framework for Supporting Pupils with Complex additional support needs (Rees Tully and Ferguson, 2017)

Scottish Educational Review, v49 n1 p67-88 2017

ABSTRACT

This paper details the development, implementation and evaluation of the South Lanarkshire Framework for Supporting Children with Complex additional support needs ("The Framework"). The document assists Scottish schools in taking forward the Curriculum for Excellence for this group of learners and in building capacity amongst staff. The guidance and resources place emphasis on the identification of relevant and individualised learning outcomes and on teaching approaches which promote pupils' development in key areas. Seven ASN establishments in South Lanarkshire completed a pre- and post- audit of curricular practice and 24 staff completed an evaluative questionnaire. 8 staff also participated in semi-structured interviews. Analyses indicated that the Framework has influenced teachers in terms of their mind-set, practice and ability to set appropriate targets. Responses also suggested that the document has led to increased collaboration amongst staff and has been shared positively with parents. The findings are discussed in relation to implications for practice and future research directions.

Keywords: Complex additional support needs; Curriculum for Excellence; Additional Support Needs

INTRODUCTION

Child development has traditionally been conceptualised as observable, age-related stages of behaviour, which are universal for typically developing children at roughly the same age. Physical milestones such as crawling and walking, or cognitive milestones such as object permanence, are described in many child development texts and this perspective not only forms the foundation of early childhood education practice but is often the benchmark by which all children are compared (Fleer, 2006). As children enter school, it is generally assumed that they will be able to participate in social activities and learn relevant cultural skills (for example, reading and writing) which influence the development of higher mental functions.

However, universal assumptions about development do not explain pathways for all populations. For children with complex additional support needs, the assumptions made by prevalent theories of child development – that the child will pass through set stages of development

towards greater autonomy (for example, Piaget, 1964; Selman,1971) – do not hold true. In contrast, these children form a heterogeneous group: the causes of their disabilities may be unknown, or they may be due to brain trauma or a specific aetiology or syndrome. The "2group" approach to disability (Burack, 1990), suggests that there are fundamental differences in the progression of this group; whilst children with no organic cause for their impairment may show delayed development across all areas, children with different aetiologies (for example, children with a recognised genetic cause for their disability) often present with 'spiky', non-linear, cognitive profiles and demonstrate specific strengths and weaknesses in different areas. This has resulted in a plethora of research on the individual development of children with syndromes, including children with Down's Syndrome (Cicchetti and Beeghly, 1990), Fragile X syndrome (Dykens *et al.* 1994) and Prader-Willi syndrome (Cacioppo, 2002)

Despite the research which focuses on smaller homogenous groups of children, the absence of observable norms across all children with complex additional support needs explains why there is no overriding conceptual understanding of development for this group of learners within educational settings. As a result, current curricula have been largely determined by mainstream policy and pedagogy and prevalent policies of inclusion. A major driver for inclusion has been the argument that children's rights are compromised by special education since they are separated from typically developing peers and from mainstream practices. This has often led to a principled, rather than evidence-based, focus on inclusive practices and to an increased reluctance to talking about labels. Yet minimising the differences of the development of children with complex additional support needs may actually prevent the level of assessment needed to inform robust individual education plans and child-centred teaching approaches. Indeed, one review did not find a firm research base for inclusive education as a means of ensuring better outcomes for these pupils (Lindsay, 2007).

In Scotland, the implementation of the Curriculum for Excellence (Scottish Government, 2009) has enabled schools to adopt a more flexible approach to meeting their learners' needs, with a focus on the "Experiences and Outcomes" of eight key areas. Focus is placed on breadth and entitlement for *all* pupils who are expected to experience the eight key areas of the curriculum, resulting in identified "Outcomes" at three different levels ("Early", "First" and "Second"). This adoption of a general education curriculum arguably creates an expectation that all children will be able to access the "Early" level of the Scottish curriculum. This could inadvertently promote the assumption that all pupils with complex additional support needs follow a linear trajectory of development and consequently, limited attention may be given to how this group of pupils learn.

For example, some pupils may have difficulty transferring skills to new contexts or may show regression due to illness.

Norwich and Lewis (2001) suggest that a balance may need to be struck, whereby pupils with complex additional support needs may "*need more of common teaching approaches at some times, but some distinct kinds of teaching at other times"* (p.325). Similarly, Imray and Hinchcliffe (2014) propose a broad curriculum only where it is meaningful for pupils. In other words, for pupils with more profound learning difficulties, the focus of the curriculum should be on a narrower range of areas that are concrete in form and relevant to their learning needs.

The most recent curricula developed by individual schools in England attempt to achieve a balance by adopting a developmental perspective to learning and life skills, whilst including elements from mainstream subjects (Hobbs, 2009; Lacey, 2011; The Bridge School, 2013; Vale of Evesham School, 2014). Emphasis is placed on providing a relevant and personalised curriculum, with a narrower range of key areas which enable pupils to develop skills in independence and communication. These areas include: Communication and Social Development, Cognition, Self Care and Independence, and Physical and Motor Development. Whilst behaviourist approaches are still used widely to develop a pupil's abilities to carry out new skills and to break down skills into smaller, achievable tasks (for example, self-care and independence skills such as putting on/taking off a jacket), an increased emphasis is placed upon process-based learning (where the interactive process between staff and pupils takes precedence over the outcome of the task).

Yet, in both England and Scotland, evaluations of current curricular approaches for this group of learners have been scarce (Lacey, 2011). In addition, although there is an increasing body of evidence highlighting the positive impact of 'intensive interaction' as a means of encouraging pupils' interaction and communication (Firth, 2006), there are still very few evaluative studies of other specific teaching approaches. The Doran review *(The Right Help at the Right Place at the Right Time*, Doran, 2012), which reviewed educational provision for children and young people with complex additional support needs in Scotland, supported a curriculum framework for all. However, it recognised the extensive adaptations required to ensure that the "Experiences" advocated by the CfE facilitate the active engagement of pupils and lead to relevant "Outcomes". The report highlighted that many additional support needs schools had been working in isolation to ensure that learning outcomes were meaningful for those with the most significant cognitive impairments. It also recommended more specific guidance and support on the "Early" level of the curriculum and advocated the development of learning communities at local, regional and national levels, to contribute to the professional learning of teachers working in this sector.

LOCAL CONTEXT AND NEEDS ANALYSIS

The outcomes of a needs analysis conducted in South Lanarkshire in 2012 corresponded with some of the findings of the Doran review. Several Additional Support Needs (ASN) establishments in the authority had reported to their educational psychologists that they were struggling to deliver a broad curriculum, as specified by the CfE, whilst meeting pupils' individual needs. In one ASN high school within the authority, an evaluation of their implementation of the curriculum for pupils with complex additional support needs was conducted between January and June 2012 (Armstrong and Rees, 2012). Whilst there were many examples of excellent practice, the outcomes of evaluation highlighted the fact that there were no clear records of formative assessment and that targets in Additional Support Plans (ASP's) were taken directly from the CfE's Experiences and Outcomes and were often the same across a class group.

WORKING PARTY

As a result of the needs analysis and in view of the national context (Scottish Government, 2009; Doran, 2012), South Lanarkshire Psychological Services proposed the creation of an authority working party to be facilitated by Psychological Service and the authority's Inclusion Service. This was comprised of educational professionals including senior managers in ASN establishments (nursery, primary, and high schools) and educational psychologists working with pupils with complex additional support needs. Previous research has found a positive link between the involvement of key stakeholders and the success of an intervention's implementation (Salanova *et al.* 2004), and it was hoped that this would provide top-down support to staff working in this sector. The working party took place every six weeks over the course of an academic year, 20132014. The aim was to create a document which supported schools in implementing an appropriate and relevant curriculum for this group of learners, all within the context of the CfE. The process leading up to the implementation and present evaluation of the Framework is depicted in Figure 1.

Figure 1. Process leading to the implementation and evaluation of the South Lanarkshire Framework

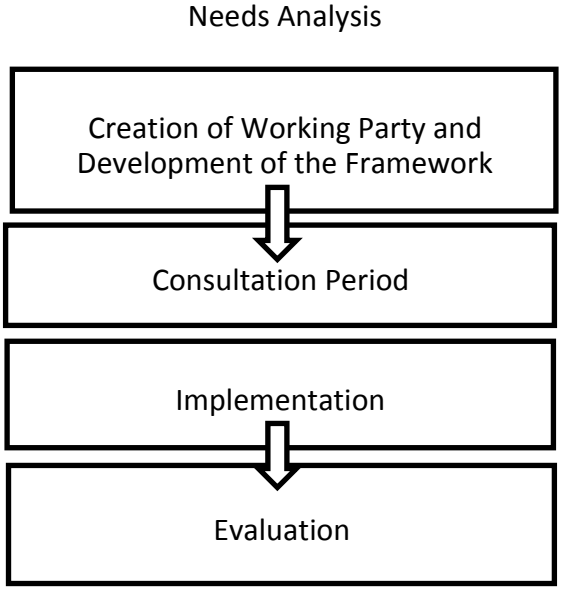


Table 1. Contents of the Framework

The contents are based on relevant literature and research on the teaching and learning of this group of learners.

DEFINITIONS

One of the first aims of the working party was to create functional definitions in response to a lack of overarching definitions in educational settings in South Lanarkshire. In England, "severe learning difficulties" (SLD) or "profound learning difficulties" (PMLD) are used. The Framework developed the definitions below to emphasise the child or young person's specific learning needs and to aid discussion about educational planning for individual pupils.

Complex additional support needs

Children and young people with complex additional support needs may have more than one disability, the most significant of which are complex additional support needs. They are likely to experience difficulties problem solving, playing co-operatively and forming relationships. Some pupils may use signs and/or symbols to communicate whilst others may use some language although this may not always be functional. Children and young people with complex additional support needs will require on-going support for most if not all aspects of daily life. They may also have:

- sensory and physical disabilities
- on-going health needs such as epilepsy

This level of disability may also exist comorbidly with other disabilities and disorders such as Autism, Down's syndrome, or other chromosomal disorders (South Lanarkshire Inclusion Service and Psychological Service (2015, p6).

Complex additional support needs

Children and young people with complex additional support needs are likely to have more than one disability, but their most significant area of need is in relation to their learning disability. They are likely to experience difficulty learning to communicate, eat, reach out and actively engage with others. These pupils are mostly non-verbal and may sometimes use eye pointing, vocalisations and gestures to communicate. Some may also use alternative augmentative communication aids. They require high levels of support with all aspects of daily life such as intimate care, feeding and clothing (South Lanarkshire Inclusion Service and Psychological Service (2015, p5).

They will also have:

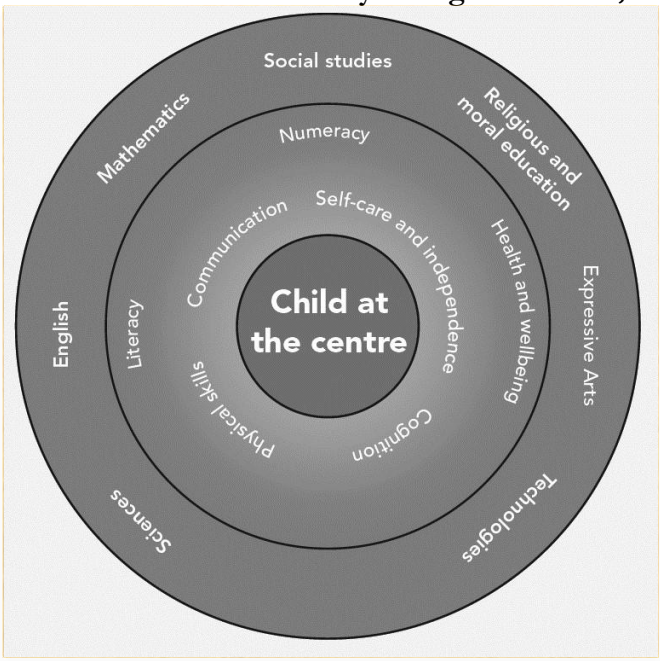
- additional sensory and physical disabilities
- multiple, complex and on-going health needs such as severe epilepsy, a gastrostomy or a tracheostomy
- a physical disability such as cerebral palsy, spina-bifida or hydrocephalus

CURRICULUM FOR EXCELLENCE

The CfE sets out every child and young person's entitlement to a broad education (Scottish Government, 2009). The Framework advises that the curriculum should be balanced with what is meaningful and relevant to the individual learning needs of the pupil. This requires staff to have an in-depth knowledge of the pupils with whom they are working and an understanding of development and progression for this group of learners. Staff will also be required to use

specialised teaching approaches. The focus will often be on key areas of the curriculum (see Figure 2.), which will enable them to develop their functional abilities. These key areas may be embedded within cross-curricular themes or subjects.

Figure 2. Key areas of the Curriculum for Excellence from the South Lanarkshire Framework (South Lanarkshire Inclusion Service and Psychological Service, 2015)



APPROACHES TO TEACHING AND LEARNING

Staff are advised to identify the specific needs, interests, and motivators of each learner with complex additional support needs. Staff should consider individual pupils' behaviours that demonstrate a high level of engagement in an activity such as stilling, eye gazing at the activity, smiling or vocalising. There should also be a balance between ensuring pupils are engaged in an activity and allowing them sufficient time to rest. The importance of the environment is highlighted in Ware's (2003) "Responsive Environment." Evidence-based teaching approaches are detailed, and related resources and links are included.

Teaching approaches include:

- Behaviourist approaches used to develop a pupil's abilities to carry out new skills
- The TEACCH approach, which addresses learning characteristics of individuals with Autism Spectrum Disorder (Mesibov, Shea, and Schopler, 2005).
- Objects and Visuals
- Picture Exchange Communication System

- Makaton/Signing and on-body signing
- Technology and I.T.
- Intensive Interaction (Firth, 2006)
- Music (for example, Sounds of Intent; Ockleford, 2000)

HEALTH AND WELL BEING AND ADDRESSING CHALLENGING BEHAVIOURS

Pupils with complex additional support needs may have a very limited repertoire of behaviours to communicate a variety of needs. In order to help staff establish the reasons for more challenging behaviours, this section provides staff with guidance on conducting a functional assessment of behaviours. Current approaches to addressing challenging behaviours advocate Positive Behaviour Support (Gore *et al.* 2013). This means that strategies to reduce or replace challenging behaviours should be used alongside interventions which develop a pupil's communication and choice making skills. Guidance is also provided on facilitating solution-focused pupil forums (see Redpath and Harker, 1999).

ASSESSMENT, MONITORING AND TARGET SETTING

Teachers are advised to provide evidence of a pupil's progress and to identify consolidated, emerging skills. The Framework provides examples of how to collate data through a variety of qualitative and quantitative assessment methods. Guidance is provided on how to conduct both formal and structured observation over time and across different situations. It is recognised that extraneous factors such as illness or a break in learning may impact negatively on previously acquired skills and may necessitate further assessment. The importance of collaboration with parents and multi-agency professionals is also highlighted.

It is recommended that the target setting process is adapted to individual needs and that targets are either task-based or process-based. Task-based targets can be broken down into small, achievable steps and encourage the development of skills (for example, carrying out daily routines). Process-based learning results in the creation of broader targets or learning intentions based on a pupil's motivators. This allows staff to be more flexible in their approach to target setting and to notice incidences of learning which occur when a child is engaged an activity.

Possible banks of targets for each of the four areas are provided in the appendix of the Framework. These were developed with reference to current curricula in England (Lacey, 2011), relevant assessments (for example, Vineland Adaptive Behaviour Scales, Sparrow et al., 1984; Schedule of Growing Skills, Williams et al, 2013) and also in liaison with teaching staff and a

physiotherapist. The targets incorporated those detailed in *Quest for Learning: Guidance & Assessment Materials, Profound & Multiple Learning Difficulties* (CCEA, 2009) which focuses on communication and cognitive skills. The banks of targets are provided as a guide to facilitate individualised target setting and it should not be presumed that pupils will progress linearly from one target to the next.

CONSULTATION

As part of the consultation process, the draft document was shared with multi-agency professionals within the ASN sector, at school and authority level, and with relevant third parties. In November 2014, the principles of the Framework and the contents of the final draft document were explained to staff at a consultation session in relevant authority ASN establishments. Those who took part in the consultation process (two ASN High schools, two ASN primary schools, an ASN Nursery, and three ASN Bases) were asked to contribute feedback by January 2015.

IMPLEMENTATION

Following the initial consultation, a number of informal consultations were held with teaching and support staff in four individual establishments. In addition, training sessions were delivered in an ASN high school, an ASN nursery and an ASN primary school in order to help staff assess the learning needs of pupils with complex additional support needs. As a result of the working party, regular staff support sessions were planned and implemented on a termly basis. These were held in a different location on each occasion and invitations were extended to all staff working in this sector across the authority. This allowed teachers and support staff to meet regularly in an informal setting to share ideas and practice.

EVALUATION

The evaluation of the Framework was carried out in three pieces of research; an audit of curricular practice; questionnaires, and semi-structured interviews. These were completed in seven ASN establishments. Eight ASN establishments initially participated in this research; however, one establishment chose not to use the Framework in their school. The seven participating establishments comprised of an ASN nursery; two ASN primary schools; two ASN high schools; two ASN primary bases and an ASN high school base. Although the two ASN primary base classes had not participated in the working party, they had begun to include children with more severe learning difficulties within their classes and had received consultation from Psychological Service regarding the document's content. They had also attended the launch of the Framework prior to participation.

The audit of curricular practice and the questionnaires helped to generate an initial picture of the effectiveness of the Framework's implementation. Semi-structured interviews were then used as a means of obtaining more in-depth perspectives regarding the Framework's usage, strengths and weaknesses.

Table 2: Number and sample for each study

	Number of participants	**Sample Population**
Audit of Curricular Practice	6	Senior managers
Questionnaire	24	Teaching staff, Senior managers and Support staff
Semi-structured interviews	8	Teaching staff and Senior managers

AUDIT OF CURRICULAR PRACTICE

Design, Measures and Procedure

This audit followed a pre- and post-evaluation design; with participants completing the audit prior to using the Framework and again six months later, after its implementation. Aversion of the How Good is Our School (HGIOS; Education Scotland, 2015) was adapted for staff supporting pupils with complex additional support needs. HGIOS is a self-evaluation tool which focuses on the impact schools have in improving the educational experience of pupils through their learning and achievements. Participants were given a series of statements on a four-point scale (1 = strongly disagree with a very significant need for action, 4 = strongly agree with no room for improvement).

These statements were split into five sub-sections:

- Creating a Responsive Learning Environment (eight items; for example: *"intimate care is planned for individual pupils".)*

- Approaches to Teaching and Learning (twelve items; for example: "*Staff allow waiting time to enable pupils to process information"*)

- Communication (eight items; for example: *"Staff are trained in and use total communication methods which are based on an assessment of pupils' needs (e.g. Makaton, PECS)."*

- Assessment and Monitoring (eighteen items; for example: "*Targets are skills-based and process based").*

- Health and Well-being and Addressing Challenging Behaviours (ten items; for example: "*Strategies are incorporated into the pupil's ASP")*

Before completing the questionnaire, members of senior management completed the audit in conjunction with relevant teachers and support staff. Thus, whilst only one audit was completed from each of the participating establishments, the responses are reflective of the wider staff team.

Results

A series of paired samples t-tests were conducted on each of the five sub-sections. From pre-test to post-test, four of the five dependent measures showed a statistically significant difference tending towards improvement (see Table 3). The post-test score for *Creating a responsive learning environment* did not reach statistical significance $t(5) = 2.45$, $p = .058$. However, compared to pretest scores, post-test scores were significantly greater for *Approaches to Teaching and Learning* $t(5) = 5.97$, $p = .002$, *Communication* $t(5) = 7.01$, $p = .001$, *Assessment, monitoring and target setting* $t(5) = 3.22$, $p = .018$ and *Health and well-being and addressing challenging behaviours* $t(5) = 3.95$, $p = .011$.

Table 3: Scores on dependent measures

Measure	Pre-test mean (*SD*)	Post-test mean (*SD*)	*t*	*p*
Creating a responsive learning environment	3.4 (0.36)	3.75 (0.19)	**2.45**	.058
Approaches to teaching and learning	2.80 (0.58)	3.44 (0.45)	**5.97**	.002**
Communication	3.33 (0.22)	3.68 (0.23)	**7.01**	.001**
Assessment, monitoring and target setting	3.07 (0.33)	3.64 (0.28)	**3.22**	.013*
Health and well-being and assessing and	3.1 (0.62)	3.73 (0.41)	**3.95**	.011*

addressing challenging behaviours

p < .05; **p < .01; ***p < .001

QUESTIONNAIRE

Design, Measures and Procedure

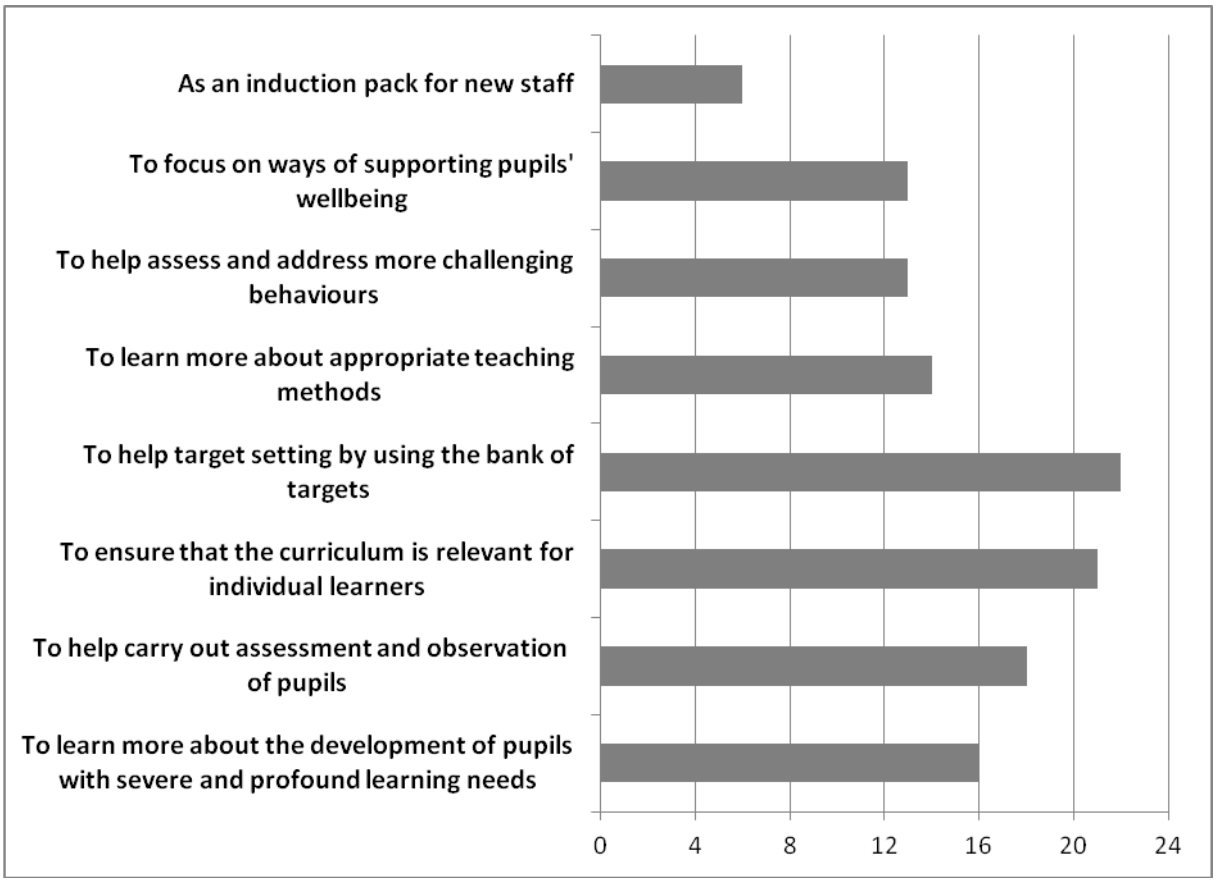
The questionnaire contained three yes/no questions *('Have you read/used/shared the Framework?'*) and one question on a 3-point scale, which asked respondents to rate the Framework's usefulness (0 = not useful, 2 = very useful). Respondents were also asked to determine ways in which they had applied the Framework to practice. Space was also provided at the end of the questionnaire for any additional comments about the Framework and needs which had arisen from its usage. The questionnaire was made available online after the Framework had been used for six months, and shared with respondents via their senior manager, who had previously facilitated the completion of the audit.

Results

23 of 24 respondents reported that they had read the Framework and applied it in their practice and all respondents rated it as very useful. 20 of the 24 respondents also reported having shared information about the Framework with other colleagues.

Usage of the Framework in teachers' practice is depicted in Figure 3. Only one question was answered with a less than 50% affirmation rate ("*Use as an induction pack for new staff").* In particular, the bank of targets was used widely, and the Framework was commonly used to ensure that the curriculum was relevant for this group of learners.

Figure 3: Use of the Framework in practice



From a total of 13 individual responses about ways in which staff had used the Framework, 29 qualitative comments were extracted and underwent thematic analysis. Six specific themes, outlined below with examples, were elicited:

- Informing Target Setting (eight comments) "The bank of targets has really focused our ASP targets and given us ideas about how to break them down."
- Informing Teacher Planning (four comments) "The Framework has been given to two new teachers to support their planning for our most complex learners."
- Making changes to individual teaching practice (six comments) "Fab resource and Framework to direct and improve practice."
- Making changes at a whole school level (three comments) "It is part of the establishment improvement plan to develop the use of the Framework guidelines."
- Using the materials and resources (three comments) "Materials have been used by myself during inset days to help staff when recording observations"
- To support new staff (two comments) "I would use the pack more as an induction pack moving forward."

SEMI-STRUCTURED INTERVIEWS

Participants

Eight members of teaching staff and senior management from the seven ASN establishments participated in the semi-structured interviews. Interviewees were classroom teachers or senior teachers with a responsibility for pupils with complex additional support needs. Participants were pooled from the previous audit and questionnaire respondents and were contacted by researchers via the senior manager in each school.

Design, Measures and Procedure

The semi-structured interviews were conceptually similar to the previous audit and questionnaire but aimed to extract more in-depth feedback regarding how the Framework had impacted practice and pupil and staff outcomes. Interviewers asked both closed questions (for example, *"Which sections have you applied to your practice; Which sections have been the most useful?"*) and open-ended questions (for example, "*What about your understanding of the development of pupils with complex additional support needs?"*)

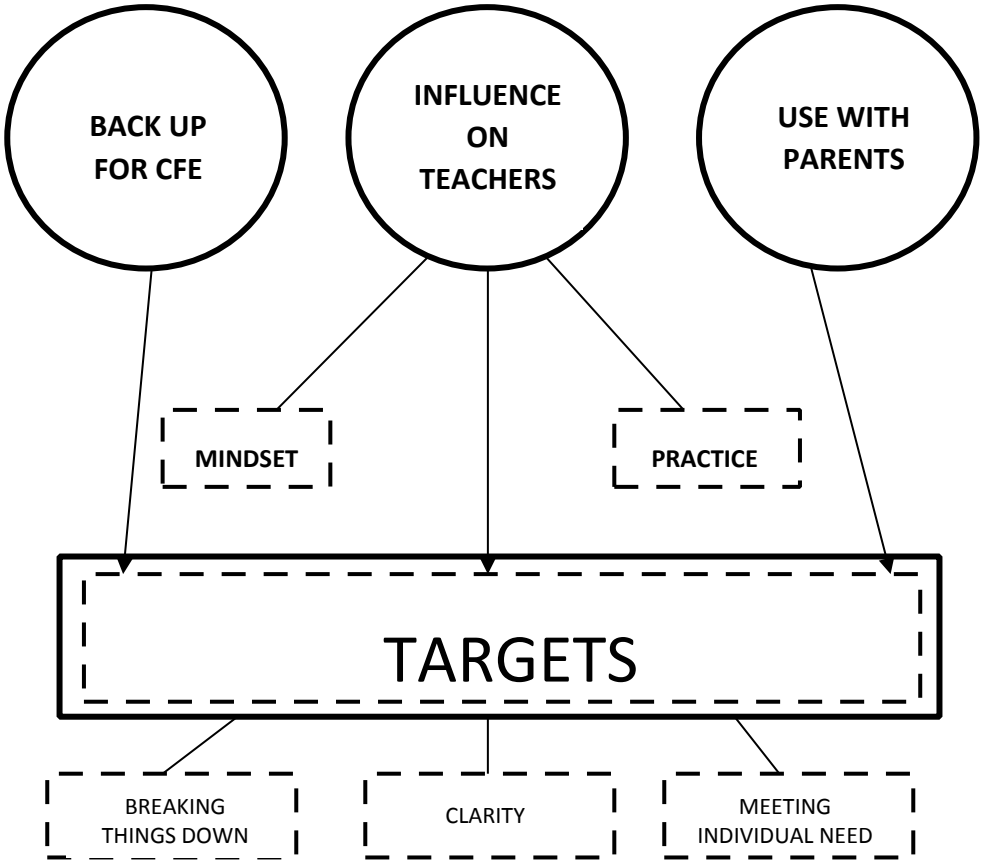
Interviews lasting between 25 and 40 minutes were conducted on an individual basis by either one of two Psychological Service research assistants or the senior educational psychologist involved in the evaluation. As the senior educational psychologist had a role in facilitating the initial working party and contributing to the document's development, it was agreed that the research assistants would conduct five of the eight interviews, whilst the educational psychologist would carry out interviews in three establishments in which she was not the assigned psychologist, and was therefore unlikely to know the participant well. This decision was made on the basis that interviewers following a qualitative approach should be objective and neutral (Ritchie *et al.* 2014).

ANALYSIS

Interviews were audio recorded and then transcribed verbatim by the research assistants before analysis commenced. Thematic analysis, influenced by Grounded Theory (Glaser and Strauss, 1967), was used in order to elicit and analyse themes and sub-themes from the data. The three researchers used an inductive approach in order to avoid fitting themes into any preconceptions. Transcripts were read and re-read during the process of analysis and comments were initially coded through conceptual labels. The interconnections between concepts were explored and then divided into themes and transferred onto a grid, with relevant extracts from the transcripts. The researchers met on several occasions to provide further evidence of support or to challenge emerging themes,

although time constraints did not allow for member checking. Themes identified were those which were the most prevalent in the data. Initial analysis generated six main themes; these were further broken down into four main themes and relevant sub-themes. The links between themes and subthemes are represented in Figure 4.

Figure 4: Main and Sub-Themes elicited following Thematic Analysis



NB: Main and subthemes are represented by their outline;

MAIN THEME═

SUB THEME = ━ ━ -

BACKUP FOR CfE

Comments inferred that the CfE in itself was insufficient for this group of learners. All participants made reference to the contents of the Framework providing backup to the CfE and that it enabled them to apply the curriculum in a more meaningful way. These comments were separated into two strands: one where the Framework verified teachers' initial professional judgements and another where the Framework acted as more of guide.

Verification

- *"It's sort of back up to what you're feeling or what you're thinking."*
- *"Seeing them [the contents of the Framework] written down, in black and white. That's what I do, that's what I do, that's what I do. And I don't need to justify it."*

  "It's probably given us the confidence to say we're on the right tracks because this is South Lanarkshire council who are saying to us what good practice looks like and this is what we want to do."

Guidance

- *"It's such a relief, maybe in some ways… that you can now have something that you can go to and reference."*
- *"It's not woolly anymore. It's clear."*

Although comments suggested that overall, the Framework made the CfE more relevant, several participants actually referred to the Framework as a curriculum rather than a guide. ,

- *"This is theirs. This is their curriculum – before it was always something watered down"*
- *"It is sort of our curriculum now. That's our syllabus that we use."*

INFLUENCE ON TEACHERS

Respondents reported that the implementation of the Framework had in some way influenced teachers in their establishment. This main theme was divided in to two subthemes: mindset and practice.

Mindset

The teachers' remarks demonstrate that the Framework has impacted on their mindset when working with pupils with complex additional support needs. Teachers spoke about increased confidence in a variety of ways. For example, noting an enhanced feeling of capability or a willingness to try new things in order to best meet the needs of their pupil.

- "*It's given them increased confidence to look at how they can have meaningful lessons for them that would still reflect what the Curriculum for Excellence guidelines is."*

- *"It was about giving staff confidence because I think sometimes they felt underqualified."*
- *"It gives you more confidence as a teacher– that you are planning; you are trying to do the right thing."*
- *"I think with this the teachers have had more confidence about maybe taking more risks and that's paid off because the children are now more engaged in their learning than they were before."*

Some teachers described an increased understanding of the development of this group of learners - especially amongst newer members of staff.

"I've *noticed a difference in people understanding the pupil's profile and the impact of their development needs."* *"It gives you a background if you were coming in and didn't have that knowledge."*

Whereas before, teachers had reported working in isolation to deliver the curriculum, their comments described the experience of being part of a network of teachers, leading to reduced feelings of isolation.

"But we're all making up the same things. So, it's quite good to see that we're not isolated, which is what we were becoming."

Practice

The participating teachers described improved and more coherent planning which positively impacted on practice.

"I found it useful for support staff and myself and teaching staff to be coming from the same place."

"Everybody's aware of what you're actually working towards."

Responses also commonly referred to directly applying aspects of the Framework in classroom practice by making use of the links and resources provided.

"We're doing the assessment that is suggested in it."

"So, I can then go through [the observation form] and highlight [when targets have been achieved]. That was really useful."

"It was using that as a tool to make people really carefully plan their lessons and programmes of work." There were several suggestions that the contents of the Framework had reduced the teacher's workload.

- *"It has to make the teacher's life easier... And it does."*
- *"I think is presented in a really useful way, there's not too much information. You can find what you need quickly."*

Several participants reported specifically that they had taken forward the four key areas that had been highlighted in the document and embedded these within the eight key areas of the Curriculum for Excellence:

- *"We are linking communication, with literacy and cognition with numeracy because it makes sense."*
- *"Having the four areas, that was like a light bulb moment, I thought that was amazing."*

PARENTS

Some participants stated that the Framework had resulted in clearer dialogue with parents, by reassuring parents that their child's learning needs were being addressed and providing further understanding of key areas of the curriculum and suitable targets for their child.

"I've been able to use that with the parents and say look, we build a curriculum around the child"

"They can see that actually their child is following a curriculum and it's very clear what they have been doing so it's really helpful as a Framework."

TARGETS

Target setting was mentioned on numerous occasions throughout the interviews by all participants. Due its thematic pervasiveness, it is presented as a main theme. However, since it is also interwoven within each of the aforementioned main themes, it is also depicted as a subtheme (see Figure 4). It can be considered to be a special subtheme.

TARGETS AS A SUBTHEME

The following demonstrate how Targets was conceptualised as a subtheme for each main theme:

Backup for CfE

- *"I think we've just found it quite helpful knowing that targets that we thought were appropriate for a child are actually appropriate. And that we now can actually use them."*

Influence on Teachers

- *"You know that there's somewhere that you can start, and you know that you could use that as a target."*

Parents

- *"Some parents have said in the past 'why are you doing that?' and you're able to say well, this all fits into part of our programme. This is the Framework we are using. So, with parents it is good, and they can look at it."*

TARGETS AS A MAIN THEME

However, in addition to its role as an integrated theme, Targets also stood as a main theme in and of itself from which three unique subthemes developed.

Breaking things down

There are many references to 'breaking down' targets and to 'small steps' suggesting that the targets previously used were too broad and less relevant to this group of learners.

- *"Reduce everything down to manageable chunks and set targets that were achievable."*
- *"And it's been broken down into tiny wee steps for them, they've known what I've been looking for. And it's been good in that way, I think it's been more rigorous for the pupils."*
  - *"And because you were breaking it down to do the ASPs, or do the targets, it helps you really focus on, right, these are baby steps, like; trying to get them to sit, shared attention, trying to do all that, the basic stuff."*

Clarity

Comments alluded to an enhanced clarity in what constituted an appropriate target and how that can be integrated into pupil progress.

- *"It's clearer cut. It was maybe not as clear cut before."*
- *"It gives you a more progressive approach... You can get a starting point for children and then you can think right, where are we going next? And you get progressions and that's meaningful."*

Meeting individual needs

Participants stated that the target setting has allowed teachers to be more attentive to individual needs.

> *"So, the target setting had to tie in with strategies and it had to tie in with knowledge of the pupil"*
>
> *"We were able to focus on the type of targets that the children needed, rather than trying to fit them into targets that we were really struggling with."*

The comments reflect people's regular reference to the possible banks of targets which are included in an appendix and which reflect the four key areas embedded within the Curriculum (physical skills; communication; cognition; self-care and independence). Comments also highlight the fact that participants understand that these provide a guide to inform target setting – rather than a prescriptive and linear set of skills to be taught.

"I've been reinforcing the fact that these are suggestions, and that it's not one size fits all. We've used the appendices to direct people so for the examples of how to do the target setting or some of the links." Consistent

with the intended purpose of the bank of targets, teachers appreciate being able to use them flexibly with their pupils, who do not follow a linear progression.

> *"You couldn't follow it through like a progression. You couldn't do that because their profiles are so jaggy but it's useful to have that (the possible banks of targets) language and then the targets after it." It's not prescriptive– it's a guideline."*

However, some teachers mentioned that other members of staff were using the bank of targets rigidly as a set of skills to be taught and completed:

> *"Some of them had gone straight to there and looked at things [the possible targets] and had instantly wanted to cut and paste."*

DISCUSSION

Consistent with the recommendations of the Doran review, the results indicate that the Framework has built: "*on the developments in guidance and advice on meeting the curricular and learning needs of children and young people with complex additional support needs within the Framework of Curriculum for Excellence"* (Doran, 2012, p. 30). There were significant differences in mean scores across four of the five sub-sections in the audit of curricular practice. Whilst this data should be interpreted cautiously due to the small sample size, the results correspond with the additional data from the questionnaire and semi-structured interviews. The semi-structured interviews, in particular, provide more detail about the positive influence on teachers' mind-set, practice and the usefulness of the resources provided within the Framework. Another key finding was the reduced feelings of isolation and increased collaboration at a local level. This in part is reflective of the Doran review's recommendation that a learning community of professionals at local, regional and national levels be developed to support staff working with children and young people with complex additional support needs.

A dominant theme concerned teachers' clearer understanding of what constitutes progress for individual learners. The guidance within the Framework appeared to allow teachers to set more appropriate and subsequently meaningful targets. The usefulness of the banks of targets provided for each of the four identified key areas was referred to throughout all stages of the evaluation by the participants. Indeed, the frequency with which it was mentioned resulted in "target setting" being defined as both a subtheme and a main theme in the analysis. Whilst the majority of interviewees noted using the banks of targets as a guide and not as a "one size fits all", some caution is noted since two participants referred to other staff "cutting and pasting" targets rather

than tailoring them to individual need. This suggests that some staff may try to compartmentalise pupils' learning and "teach to target", rather than basing teaching on a broader assessment of a child's needs. However, by recommending both task and process-based targets, the Framework aims to encourage staff to focus on the teaching of specific skills whilst paying attention to examples of incidental learning. These emerge as a result of activities which are based on children's motivators and which facilitate their active engagement and interaction with staff.

The extent to which participants referred to using the target setting information within the Framework indicates that staff benefited from resources which enabled them to assess progress and plan learning outcomes based on individual need. This also highlights a potential discord with broader, cultural assumptions of a linear trajectory of development and set stages of development, which are often embedded within mainstream pedagogy. Interestingly, participants in the semi structured interviews had worked in this sector for a considerable length of time and portrayed a deep understanding of the pupils with whom they worked. Most participants did not claim that the Framework significantly increased their understanding of the pupils' development (although some participants suggested that this may be the case for staff new to this sector), but rather that they felt a sense of permission that what they deemed to be important for pupils' progress still accorded with the principles of the CfE. According to Imray and Hinchcliffe (2014, p 42);

> *"...the underlying assumptions of a curriculum should be challenged when applied to this group of learners: Those with SLD and especially those with PMLD, are by definition, unlikely to achieve academic success and we must be prepared to challenge the view that persisting with an academic pedagogy and curriculum because it's what everyone does is sufficient in itself — it's not."*

From the semi-structured interviews, some participants reported that parents have already responded positively to the Framework. Two participating teachers also mentioned that parental perceptions of progress often differ to those stipulated by the CfE. This suggests a possible mismatch between conceptualisations of progress as defined by parents versus those defined by the curriculum and is an issue which could benefit from further exploration, particularly as the needs of this particular group of learners requires close collaboration between teachers and parents.

There is also limited research which explores the attainment of pupils with complex additional support needs, explained perhaps by the complexity of these pupils' needs. A small-scale evaluation of pupils' progress over a four-year period noted that pupils' achievements were also dependent on extraneous factors such as ill health and therapy interventions (Hobbs, 2009). Next steps may therefore be to explore pupils' attainment through an analysis of targets and progress recorded in individual ASPs, both before and since the implementation of the Framework. This

may help to ascertain the extent to which the Framework has facilitated appropriate target setting. It may also be beneficial to consider how ASP targets can be tracked using more structured, lateral methods, taking into account important aspects of a pupil's progress (for example, increased independence, increased focus and attention on a task, transfer of a target to different environment). Indeed, one of the participants had indicated that a more structured means of assessment would be beneficial within the classroom and would supplement the tools which she typically uses to track progress.

LIMITATIONS

This evaluative study provides an example of real-life, school-based research (Robson, 2002) and comes with associated practical constraints. There are a limited number of establishments in South Lanarkshire accommodating pupils with complex additional support needs. This resulted in a small sample size and also prevented the inclusion of a control group. In addition, there were several staff changes in establishments between the collection of the pre- and post- data. This small sample size was of particular note during the audit, where inferential statistical analyses were used. However, the data from the semi-structured interviews was consistent with the findings of the audit.

CONCLUSION

The South Lanarkshire Framework for supporting pupils with complex additional support needs was developed as a result of both a local needs analysis and national priorities. The evaluative study provides initial data about the positive impact of the Framework on teacher practice (clearer and more consistent curriculum planning; assessment and teaching approaches) and mind-set (increased confidence, understanding and reduced feelings of isolation). Significantly, participants suggested the Framework has provided a clearer way of setting targets that is based on an assessment of a pupil's learning needs, rather than on common conceptions of development which assume a linear trajectory.

In accordance with the outcomes of the Doran review (Doran, 2012), the findings suggest that the Framework has led to the development of a 'local learning community' of staff working in this sector which has increased collaboration and the sharing of good practice. This may be beneficial for staff, not only in terms of understanding development, but also in terms of challenging assumptions of the curriculum and developing further evidence-based methods of the teaching and assessment. The evaluation also provides further direction for more rigorous

evaluations of the impact of the Framework on pupil attainment and for the establishment of more structured means of assessing children with complex additional support needs.

This evaluation was supported by South Lanarkshire Psychological Service and South Lanarkshire Inclusion Service. Thanks, are also extended to colleagues from ASN establishments across the authority who contributed to the contents of the South Lanarkshire Framework for Supporting Pupils with Complex additional support needs and who took part in the evaluation. An electronic version of the document is available on: http://www.southlanarkshire.gov.uk/downloads/file/9818/framework_for_supporting_pupils_with_severe_and_profound_learning_needs#

REFERENCES

Armstrong, I. & Rees, K. (2012) *Evaluation of the Curriculum for Children with Severe and Complex Needs in Sanderson High School*, unpublished manuscript, South Lanarkshire Psychological Service.

The Bridge School (2013) *Curriculum for Pupils with Complex additional support needs.* Online at http://www.thebridgelondon.co.uk/assets/filemanager/downloads/The%20Bridge%20PMLD%20Curriculum%202013.pdf (Accessed 16/9/16).

Burack, J.A. (1990) *Differentiating Mental Retardation: The Two-group Approach and Beyond.* In: R.M Harappa, J.A. Burack, & E. Zigler (Eds.) *Issues in the Developmental Approach to Mental Retardation.* Cambridge: Cambridge University Press (p. 27-44).

Cacioppo, J. T. (2002) Social Neuroscience: Understanding the Pieces Fosters Understanding the Whole and Vice Versa, *American Psychologist,* 57(11), 819-831.

Cicchetti, D. & Beeghly, M. (1990) *Children with Down Syndrome: A Developmental Perspective.* Cambridge: Cambridge University Press.

Council for Curriculum, Examinations & Assessment (CCEA) (2009). *Quest for Learning.* Guidance & Assessment Materials Profound & Multiple Learning Difficulties'. Belfast: CCEA.

Doran, P. (2012) *The Right Help at the Right Time at the Right Place: Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs*, The Scottish Government. Online at http://www.gov.scot/Resource/0040/00408307.pdf (Accessed 16th September, 2017).

Dykens, E.M., Hodapp, R.M. & Leckman, J.F. (1994) *Behavior and Development in Fragile X Syndrome.* Thousand Oaks, CA: Sage Publications.

Education Scotland *(2015) How Good is Our School?,* 4th edition, Education Scotland, September 2015, http://www.educationscotland.gov.uk/Images/HGIOS4_tcm4-870533, accessed December 12th, 2015

Firth, G. (2006) Intensive Interaction: A Research Review, *Mental Health and Learning Disabilities Research and Practice*, 3(1), 53-62.

Fleer, M. (2006) The Cultural Construction of Child Development: Creating Institutional and Cultural Intersubjectivity, *International Journal of Early Years Education*, 14(2), 127-140.

Glaser, B. G. & Strauss, A.L. (1967) *The Discovery of Grounded Theory,* Chicago: Aldine.

Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, J.C., Baker, P., Hastings, R.P., No-one, S.J. & Denne, L.D., (2013) Definition and Scope for Positive Behavioural Support, *International Journal of Positive Behavioural Support,* 3(2), 14-23.

Hobbs, V. (2009) Maximising the progress of learners with profound and multiple learning difficulties, *The SLD Experience,* 55(1) 10-16.

Imray, P. & Hinchcliffe, V. (2014) *Curricula for Teaching Children with Severe or Profound and Multiple Learning Difficulties.* Abingdon: Routledge.

Lacey, P. (2011) Developing a Curriculum for Pupils with PMLD, *The SLD Experience,* 61(1), 4-7.

Lawson, H., Waite, S. & Robertson, C. (2005) Distinctiveness of Curriculum Provision at 14 to 16 for Students with Learning Difficulties: Opportunities and Challenges, *British Journal of Special Education*, 32(1),12-20.

Lindsay, G. (2007) Educational Psychology and the Effectiveness of Inclusive Education/Mainstreaming, *British Journal of Educational Psychology,* 77(1), 1-24.

McBrien, J. & Foxen, T. (1981) *Training Staff in Behavioural Methods: The EDY In-service Course for Mental Handicap Practitioners: Instructor's handbook*. Manchester: Manchester University Press.

McClimens, A. (2005) From Vagabonds to Victorian Values: The Social Construction of a Disability Identity. In G. Grant, P Goward, M. Richardson & Ramcharan, P. (Eds.) *Learning Disability: A Life Cycle Approach to Valuing People*, Berkshire: Open University Press (p. 28-46).

Mesibov, G. B., Shea, V., & Schopler, E. (2005). The TEACCH approach to autism spectrum disorders. Springer Science & Business Media.

Northern Ireland Curriculum (2011) *Quest for Learning.* Online at http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pmld/quest_guidance_booklet.pdf (Accessed 16/9/16).

Norwich, B. & Lewis, A. (2001) Mapping a Pedagogy for Special Educational Needs, *British Educational Research Journal*, 27(3), 313-329.

Norwich, B. (2002) Education, Inclusion and Individual Differences: Recognising and Resolving Dilemmas, *British Journal of Educational Studies,* 50(4), 482-502.

O' Brien, S.J. (1988) For Parents Particularly: Childhood Stress: A Creeping Phenomenon, *Childhood Education*, 65(2), 105-106.

Ockelford, A. (2000) Music in the Education of Children with Severe or Profound Learning Difficulties: Issues in Current UK Provision, a New Conceptual Framework, and Proposals for Research, *Psychology of Music,* 28(2), 197-217.

Piaget, J. (1964). Part I: Cognitive Development in Children: Piaget, Development and Learning, *Journal of Research in Science Teaching*, 2(3), 176-186.

Redpath, R., & Harker, M. (1999) Becoming Solution- Focused in Practice, *Educational Psychology in Practice,* 15(2), 116-121.

Ritchie, J., Lewis, J., Nicholls, C.M. & Ormston, R. (2014) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, 2nd Ed, London: Sage.

Robson, C. (2002) *Real World Research,* 3rd Ed, Oxford: Blackwell.

Salanova, M., Cifre, E. & Martin, P. (2004) Information Technology Implementation Styles and their Relation with Workers' Subjective Well-being, *International Journal of Operations & Production Management*, 24(1), 42-54.

Scottish Government (2009) The Curriculum for Excellence. Edinburgh; Scottish Government. Available at: www.educationscotland.gov.uk/Images/all-experinces-outcomes-tem4-539562.pdf, accessed 24th July 2016

Selman, R.L. (1971) The Relation of Role-Taking Ability to the Development of Moral Judgement in Children, *Child Development,* 42, 79-91.

South Lanarkshire Inclusion Service and Psychological Service (2015) *The South Lanarkshire Framework for supporting pupils with complex additional support needs*. South Lanarkshire: South Lanarkshire Council.

Sparrow, S.S., Balla, D.A. & Cicchetti, D.V. (1984) *Vineland Adaptive Behaviour Scales.* Minneapolis: American Guidance Services.

The Bridge School (2013) *Curriculum for Pupils with Complex additional support needs.* Online at http://www.thebridgelondon.co.uk/assets/filemanager/downloads/The%20Bridge%20PMLD%20Curriculum%202013.pdf (Accessed 16/9/16).

Vale of Evesham School (2014) *Vale of Evesham School Profound and Multiple Learning Difficulties Curriculum*. Online at http://valeofeveshamschool.org/Links/curriculum/pmld%20curriculum/vale%20of%20Evesham%20PMLD%20Curriculum.pdf (Accessed 16/9/16).

Waite, J., Heald, M., Wilde, L., Woodcock, K., Welham, A., Adams, D. & Oliver, C. (2014) The Importance of Understanding the Behavioural Phenotypes of Genetic Syndromes Associated with Intellectual Disability, *Paediatrics and Child Health*, 24(10), 468-472.

Ware, J. (2003) *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties,* 2nd Ed, London: David Fulton Publishers Ltd.

Welsh Assembly Government (2006) *Routes for Learning Additional Guidance: Assessment Materials for Learners with Profound Learning Difficulties and Disabilities.* Online at http://learning.gov.wales/docs/learningwales/publications/121115routeslearningadditionalen.pdf (Accessed 16/9/16).

Williams, M.E., Hutchings, J., Bywater, T., Daley, D. & Whittaker, C.J. (2013) Schedule of Growing Skills II: Pilot Study of an Alternative Scoring Method, *Psychology*, 4(3), 143-152.

APPENDIX 3. Interviews

Questions to Elicit Individual Conceptualisations of Development

Tell me about your/the/the child's learning needs.

Tell me a bit about your/the child… What is he/she good at? (his/her strengths) What does he/she find more difficult?

What motivates him/her? What are his/her likes/dislikes? How do you know?

How does your/the child communicate his or her needs? (e.g. that he/she wants something/doesn't like something)

How would you compare your/the child's development and progress to that of other children?

What to you, are the most important aspects of your/the child's development? (E.g. what is a main focus for you? What is it important that he/she learns to do? Why?)

What practices/strategies do you use to try and encourage his or her development in these areas?

Have you made any changes to the toys you use/environment in order to engage your/the child in an activity or to help their progress?

Has anyone or anything really influenced the way you think about your/the child's development? (E.g. really helped you to understand your/the child's development; or changed the way you think about their development.) (E.g. This may be family members; professionals; programmes your/the child has been involved in; organisations; things you have read; your/the child)

Can you describe any meaningful moments regarding your/the child's development and progress?

What progress has your/the child made recently?

What is currently helping –or who is helping your/the child to make progress?

Has anyone or anything helped you to understand what you and others can be doing to develop your/the child's abilities?(e.g. This may be family members; professionals; programmes your/the child has been involved in; organisations; things you have read; your/the child)

Is there anything else that could help your/the child's development?

What targets are staff working on in the nursery/home setting? How does this compare to things you are focusing?

Do you share your/the views and beliefs about your/the child's development with the nursery/parents? And with other professionals ? How have you shared your/the views? How do you find this?

Have your/the views about your/the child's development changed over time – since your/the child was born or since their diagnosis? If so, why do you think this is? What has made them change?

Is there anything that is preventing your/the child from making progress?

Has your/the child's development surprised you in any way?

What does progress look like for your/the child?

Is there anything else you wish to add or share about your/the child's development and progress?

APPENDIX 4. Ethics Forms

APPENDIX 4.1 Ethics Approval Letter - University of Dundee

School of Education and Social Work

School Research Ethics Committee

MS/JL/E2016-123

School of Education and Social Work
University of Dundee
Nethergate
Dundee
DD1 4HN

24th April 2017

Dear Kirstie Rees,

E2016-123

Title: Exploring conceptualisations of development amongst parents and teachers of young children with severe learning

I am pleased to confirm that there are no ethical issues with the above application, therefore this has now been formally approved.

Yours sincerely

Dr Murray Simpson
Convenor, ESW Research Ethics Committee

APPENDIX 4.2. Ethics Approval Letter South Lanarkshire Council

SOUTH LANARKSHIRE COUNCIL
Education Resources
Executive Director Tony McDaid
Curriculum & Quality Improvement Service

Kirstie Rees
Psychological Service
c/o St Andrew's & St Bride's High School
Clathorn Drive
East Kilbride
G74 NJL

Our ref: EDU/RESEARCH/TK
Your ref:
If calling ask for: Tracy Kerr
Phone: 01698 454434
Date: 09 June 2019

Dear Kirstie

Access to Undertake Research

Title : Conceptualisations of the Development of Children with Severe and Profound Learning Difficulties: Perspectives of Parents and Nursery Staff

Thank you for your application form, requesting access to undertake research with South Lanarkshire Council, Education Resources.

I am pleased to advise you that approval has been granted for you to contact the Head Teachers of schools with nurseries in South Lanarkshire to ask if they will take part in your project.

When you contact the Head Teachers you should enclose/attach a copy of this letter as proof of authorisation. Each Head Teacher will have the final veto over whether or not his or her establishment shall participate.

You should ensure complete confidentiality of both establishments and individuals at all times.

I wish you every success with your research and if I can be of any further assistance please contact me at the address below.

Yours sincerely

Tracy Kerr

Tracy Kerr
Management Information Assistant

Council Offices, Almada Street, Hamilton ML3 0AE Phone: 01698 454434 Fax: 01698 454465
Email: tracy.kerr@southlanarkshire.gsx.gov.uk

I:\Quality\Management Information\Research\2018-2019\Kirstie Rees\Letter Approval.doc

APPENDIX 4.3. Parent and Nursery Staff Letter and Consent

Dear

I am writing to ask you to take part in an interview for a research. The aim of the project is to find out more about parents' and nursery staff views about the development of children with learning difficulties. I enclose an information leaflet and will be very happy to discuss any questions that you might have.

If you are interested in participating in the interview, I would be grateful if you could you r eturn

the completed informed consent form in the envelope provided.

Yours Faithfully

Kirstie Rees

Senior Educational Psychologist

Doctoral Student at Dundee University

Research Study:

Parents and Nursery Staff Views about the development of children with learning difficulties

INFORMED CONSENT FORM

	Yes *(please tick)*
I have read and understood the information that I have been given	
I have had time to think about the information	
I have had the opportunity to ask any questions about the interview and about the questions that I will be asked	
I understand that the views that I give will be analysed for the research, but that my name and details will be anonymised	
I understand that the interview will be audiotaped and then typed up so that it can be analysed.	
I understand that my participation in this research is entirely voluntary and that I can withdraw at any point. If I decide to withdraw, I can ask for my data to be withdrawn from the research	

I agree to take part in the study

…….

(Full name)

…….. ……

(Please sign your name)

……..

(Date)Thank you for completing this form

APPENDI X 4.4. Parent Information Leaflet

What if you change your mind about participating?

Your participation in this research is voluntary. Whether or not you participate will not affect you or your child in any way. You have the right to withdraw your consent at any time and to refuse to answer particular questions.

I hope, however, that having the opportunity to sit and talk with me about your child's development will be useful for you, your child and your nursery and will help you to think more clearly about your child's progress.

What if you want more information?

I am happy to provide more information. If you have any questions about the study, please contact me at:

Psychological Service,
c/o St Andrew's and St Bride's High School.
Platthorn Drive, East Kilbride G74 1NL
Telephone: 01355 574121
Email: k.z.rees@dundee.ac.uk

Research Study on the development of children with learning difficulties

Information Leaflet for Parents

Kirstie Rees
Senior Educational Psychologist
South Lanarkshire Psychological Service
Doctoral Student at Dundee University

What is the research about?

I am conducting research on the development of children and young people with learning difficulties as part of a Doctorate at Dundee University. The overall aim of the Doctorate is to look at ways of helping parents and staff work together to help a child to make progress.

This first research study aims to find out about parents' and nursery staff views about the development of children with learning difficulties.

What will you have to do?

You will be invited to take part in a one-to-one interview with me. This will take about approximately 45 minutes to one hour. You can decide where it takes place and it will happen at a time convenient to you. A member of the nursery staff will be asked to take part in an interview with me at another time.

What will you be asked about?

- Your child's strengths, difficulties and diagnosis
- What you think are important aspects of his or her development
- What has influenced what you think about your child's development
- What/whom is helping his or her progress
- What you are doing to help your child to make progress
- How you share what you think about your child's development with nursery and others

Some of the questions may make you think about some emotional and challenging experiences. If you find some of the questions difficult and want to discuss things further, I will talk to you about possible avenues of support.

How will your answers be recorded?

- The conversation will be audiotaped and then typed up so that it can be analysed.
- The names of participants, children, nurseries and other people mentioned will be changed and kept anonymous.
- The contents of the interview will not be shared with the nursery or with any other professionals.
- The recording of our interview will be kept in a secure location.
- Like other Doctoral research, the recordings will be destroyed 5 years after the Doctorate has been completed.

What will happen with the questions you give?

The important information from the interviews will be analysed and written up as part of the Doctorate. Short quotes from the interviews will be included.

You will also be given the opportunity to learn about the findings.

APPENDIX 4.5. Nursery Staff Information Leaflet

What if you change your mind about participating?

Your participation in this research is voluntary. Whether or not you participate will not affect you or the child in any way. You have the right to withdraw your consent at any time and to refuse to answer particular questions

I hope, however, that having the opportunity to sit and talk with me about your beliefs about the development of a child with learning difficulties will be useful for you and your nursery and will help you to think more clearly about children's progress.

What if you want more information?

I am happy to provide more information. If you have any questions about the study, please contact me at:

Psychological Service,
c/o St Andrew's and St Bride's High School.
Platthorn Drive, East Kilbride, G74 1NL
Telephone: 01355 574121
Email: k.z.rees@dundee.ac.uk

Research Study on the development of children with learning difficulties

Information Leaflet for Nursery Staff

Kirstie Rees
Senior Educational Psychologist
South Lanarkshire Psychological Service
Doctoral Student at Dundee University

What is the research about?

I am conducting research on the development of children and young people with learning difficulties as part of a Doctorate at Dundee University. The overall aim of the Doctorate is to look at ways of helping parents and staff work together to help a child to make progress.

This first research study aims to find out about parents' and nursery staff views about the development of children with learning difficulties.

What will you have to do?

You will be invited to take part in a one-to-one interview with me. This will take about 45 minutes to one hour. It will happen in the nursery and at a time convenient to you. The child's parent will be asked to take part in an interview with me at a different time.

What will you be asked about?

- The strengths, difficulties and diagnosis of a child with learning difficulties with whom you are working
- Important aspects of his or her development
- What has influenced what you think about the child's development
- What/whom is helping his or her progress
- What you are doing to help the child to make progress
- How you share what you think about the child's development with parents and others

How will your answers be recorded?

- The conversation will be audiotaped and then typed up so that it can be analysed.
- The names of participants, children, nurseries and other people mentioned will be changed and kept anonymous.
- The contents of the interview will not be shared with the nursery or with any other professionals.
- The recording of our interview will be kept in a secure location.
- Like other Doctoral research, the recordings will be destroyed 5 years after the Doctorate has been completed.

What will happen with the questions you give?

The important information from the interviews will be analysed and written up as part of the Doctorate. Short quotes from the interviews will be included.

You will be given the opportunity to find out about the findings. The results from the research may also be presented at meetings or in educational journals.

APPENDIX 4.6. Ethics Approval Letter for Focus Group – University of Dundee

School of Education and Social Work

School Research Ethics Committee

MS/CM/E2017-88

School of Education and Social Work
University of Dundee
Nethergate
Dundee
DD1 4HN

20th May 2018

Dear Kirstie Rees

E2017-88

Title: Exploring conceptualisations of development amongst parents and teachers of young children with severe learning difficulties

I am pleased to confirm that there are no ethical issues with the above application, therefore this has now been formally approved.

Yours sincerely

Dr Murray Simpson
Convenor, ESW Research Ethics Committee

APPENDIX 4.7. Parent and Nursery Letter and Consent Form for Focus Groups

Re: Research Study on the Development of Young Children with Learning Difficulties

Many thanks for participating in the individual interviews for the above research project. The information that you provided has been very helpful.

I am writing to confirm your participation in the second stage of the study. The aim of this is to present parents and nursery staff with the themes that emerged from the interviews and to ask for your views and comments about this. There will also be an opportunity to provide further ideas about how staff and parents can work together to promote children's progress.

The discussion will take place in a focus group, comprised of a small group of parents and nursery staff. The groups will be mixed, and you will not necessarily attend the same group as your child's nursery keyworker. There will be between 4 and 8 people in a group.

You are invited to the session below:

Wednesday, 20th June 10.45-11.15

Friday, 22nd June 9.30-11.00am

XXXX NURSERY (PARENTS' ROOM TO THE LEFT OF THE FOYER)

I would be grateful if you could complete the enclosed consent form and bring it along to the focus group.

I have enclosed a leaflet and poster with further information and a plan of the themes to be discussed.

If you wish to discuss further, please contact me at the telephone number below or at either email address.

Yours Sincerely

Kirstie Rees

Senior Educational Psychologist

Doctoral Student at Dundee University

Research Study:

Parents and Nursery Staff Views about the development of children with learning difficulties

INFORMED CONSENT FORM

	Yes *(please tick)*
I have read and understood the information that I have been given	
I have had time to think about the information	
I have had the opportunity to ask any questions about the interview and about the questions that I will be asked	
I understand that the views that I give will be analysed for the research, but that my name and details will be anonymised	
I understand that the interview will be audiotaped and then typed up so that it can be analysed.	
I understand that my participation in this research is entirely voluntary and that I can withdraw at any point. If I decide to withdraw, I can ask for my data to be withdrawn from the research	
I agree to take part in the study	

…….

On ……. (Date)

(Full name)

…….. ……

(Please sign your name)

……..

(Date)

Thank you for completing this form

What if you change your mind about participating?

Your participation in this research is voluntary. Whether or not you participate will not affect you or your child in any way. You have the right to withdraw your consent at any time and to refuse to answer questions.

I hope, however, that having the opportunity to attend the group will be useful for you and will help to explore how parents and nursery staff can work together to support children's progress.

What if you want more information?

I am happy to provide more information. If you have any questions about the study, please contact me at:

Psychological Service,
c/o St Andrew's and St Bride's High School.
Platthorn Drive, East Kilbride G74 1NL
Telephone: 01355 574121
Email: k.z.rees@dundee.ac.uk

Research Study on the development of children with learning difficulties

Part 2

Information Leaflet for Nursery Staff

Kirstie Rees
Senior Educational Psychologist
South Lanarkshire Psychological Service
Doctoral Student at Dundee University

What is the research about?

I am conducting research on the development of children and young people with learning difficulties as part of a Doctorate at Dundee University. The overall aim of the Doctorate is to look at ways of helping parents and staff work together to help a child to make progress.

This first research study aims to find out about parents' and nursery staff views about the development of children with learning difficulties.

What will you have to do?

You have already taken part in a one-to-one interview with me. You are now being asked to attend a small focus group involving parents and nursery staff to learn more about the themes from the interviews. This will last approximately an hour and a half. Refreshments will be provided.

What will happen at the focus group?

Each main theme from the interviews will be presented, followed by the opportunity to comment and give your views.

The themes are:

- *How our experiences influence views about development*
- *Understanding the child's development is a learning process*
- *How we define a child's progress*
- *Focusing on important areas of progress*
- *The relationship between parents and nursery staff*

You will also be asked to think about how the findings from the interviews can help staff and parents focus on the same areas of development for your child.

There will be a maximum of 6 in the group. You will not attend the same session as your child's keyworker at nursery.

Some of the questions may make you think about some emotional and challenging experiences. If want to discuss things further either before or after the focus group, I am happy to do this. I can also talk to you about possible avenues of support. If you would like to receive further information about your original interview, I will arrange a time to discuss this with you.

How will your answers be recorded?

- The discussion will be audiotaped and then typed up so that it can be analysed.
- Like before, the names of participants, children, nurseries and other people mentioned will be changed and kept anonymous.
- The contents of the interview will not be shared with the nursery or with any other professionals.
- The recording of our interview will be kept in a secure location.
- Like other Doctoral research, the recordings will be destroyed 5 years after the Doctorate has been completed.

What will happen with the questions you give?

The important information from the interviews will be analysed and written up as part of the Doctorate. Short quotes from the interviews will be included. The findings will help to inform ways that parents and nursery staff can work together to support children's progress.

APPENDIX 4.9. Nursery Staff Information Leaflet for Focus Group

The results from the research may also be presented at meetings or in educational journals.

What if you change your mind about participating?

Your participation in this research is voluntary. Whether or not you participate will not affect you or your child in any way. You have the right to withdraw your consent at any time and to refuse to answer questions.

I hope, however, that having the opportunity to attend the group will be useful for you and will help to explore how parents and nursery staff can work together to support children's progress.

What if you want more information?

I am happy to provide more information. If you have any questions about the study, please contact me at:

Psychological Service,
c/o St Andrew's and St Bride's High School.
Platthorn Drive, East Kilbride G74 1NL
Telephone: 01355 574121
Email: k.z.rees@dundee.ac.uk

Research Study on the development of children with learning difficulties

Part 2

Information Leaflet for Nursery Staff

Kirstie Rees
Senior Educational Psychologist
South Lanarkshire Psychological Service
Doctoral Student at Dundee University

What is the research about?

I am conducting research on the development of children and young people with learning difficulties as part of a Doctorate at Dundee University. The overall aim of the Doctorate is to look at ways of helping parents and staff work together to help a child to make progress.

This first research study aims to find out about parents' and nursery staff views about the development of children with learning difficulties.

What will you have to do?

You have already taken part in a one-to-one interview with me. You are now being asked to attend a small focus group involving parents and nursery staff to learn more about the themes from the interviews. This will last approximately an hour and a half. Refreshments will be provided.

What will happen at the focus group?

Each main theme from the interviews will be presented, followed by the opportunity to comment and give your views.

The themes are:

- *How our experiences influence views about development*
- *Understanding the child's development is a learning process*
- *How we define a child's progress*
- *Focusing on important areas of progress*
- The relationship between parents and nursery staff

You will also be asked to think about how the findings from the interviews can help staff and parents focus on the same areas of development for your child.

.

There will be a maximum of 6 in the group. You will not attend the same session as your child's keyworker at nursery.

If want to discuss things further either before or after the focus group, I am happy to do this. I can also talk to you about possible avenues of support. If you would like to receive further information about your original interview, I will arrange a time to discuss this with you.

How will your answers be recorded?

- The discussion will be audiotaped and then typed up so that it can be analysed.
- Like before, the names of participants, children, nurseries and other people mentioned will be changed and kept anonymous.
- The contents of the interview will not be shared with the nursery or with any other professionals.
- The recording of our interview will be kept in a secure location.
- Like other Doctoral research, the recordings will be destroyed 5 years after the Doctorate has been completed.

What will happen with the questions you give?

The important information from the interviews will be analysed and written up as part of the Doctorate. Short quotes from the interviews will be included. The findings will help to inform ways that parents and nursery staff can work together to support children's progress.

APPENDIX 5. Focus Groups

APPENDIX 5.1. Plan of Focus Group

May 2018

Kirstie Rees DEdPsy Research Project Part 2 Focus Group

Structure, Themes, Questions and Prompts for the Focus Group

Setting the Scene – 15 minutes

Make sure tea/coffee is available – consent forms/leaflets /posters are on table

Introductions

Housekeeping: confirmation of consent forms- make sure they are signed , reference to right to withdraw; audio recording; anonymity; refreshments etc

Aims of the focus group (refer to original research)

- to explore themes
- to highlight range of views
- to confirm or disaffirm these
- to explore new and emerging themes
- to look at next steps and how to apply findings to practice)

Acknowledge advantages and disadvantages of focus group setting:

- mixed composition (not with known nursery worker)
- sometimes may be reluctant to contribute in group setting BUT
- flexible approach – can follow participants' lead
- opportunity to work together
- may hear others who hold similar views or who have had similar experiences
- opportunity to take things forward and for parents and staff to collaborate in informal setting

Refer to focus group 'ground rules' – listening to others; thinking about how their experience /context differs; ensuring all views are heard

Explain my own role as researcher, educational psychologist, mother

Structure of Discussion

Ask about interview experience

Presentation of each theme on screen; followed by prompts and open-ended questions.

Refer to the influence of context/ their own experiences on views,

Reference to new and emerging themes from data. What do they think?

Discuss next steps

Close – reminder about consent; right to withdraw; possibility of contacting me etc

Questions/Prompts

(1) The influence of Cultural Norms: Linear Development
The Vocabulary of Linear Development
Attitudes Towards Disability

Cultural Codes: The Curriculum and Nursery Environment

(2) Understanding the Child's Development is a Learning Process
Cognitive Challenge
Emotional Challenge
Diagnosis
The Role of Professionals

(3) Defining Progress Differently: - Degrees of Insightfulness
Adhering to a Linear Trajectory: Comparison with Chronological Norms
A Different Pathway
Unique and Individual Progress
Resolution and Insightfulness

(4) Focusing on 'The Basics'
Communication
Other Strategies
(5) The Relationship between Parents and Nursery Staff; trying to 'get on the same page'
Different Conceptualisations of Progress; Disempowered Parents and Staff
Working Together to Understand Conceptualisations of Development

How did you find the interview? Was it useful/difficult? In what way? Did it make them reflect in any way? 5 minutes

1. **The influence of Cultural Norms: Linear Development 10 minutes** Refer to social and cultural models of disability – what has influenced them more? How do they feel about the cultural pressure for children to attain? What about the pressure of the curriculum? Think about the vocabulary of linear development- is this part of the language they use?
2. **Understanding the Child's Development is a Learning Process 10 minutes** Cognitive challenge- research, research. Talk about emotional challenge; this is more evident for parents in the data. What about nursery staff? Do parents think nursery staff understand the emotional challenge?
3. **Defining Development Differently: - Degrees of Insightfulness 10 minutes** Present different ways of looking at progress. Fluctuating between linear and non-linear. Do their conceptualisations change over time? Has this changed since interview and why? What is a useful conceptualisation? Discuss insightfulness and what leads to this. Explore how child' presentation affected their interaction with child. Is this important? Has this changed? How do we educate others to think about the

development of children with learning difficulties? What would be helpful for staff and parents? Is training or hands- on experience more important for staff?

4. Focusing on 'The Basics' 10 minutes

Discuss narrower range of areas identified and the importance of communication. Is this still the case now, even when children are older? Indicate different strategies employed; not consistent. Are there consistent approaches that we should be recommending? How to go about evaluating these in nursery? What do parents feel about their role in target setting at nursery? Themes suggest curriculum has to be adapted or abandoned. What about tracking tool? What should be in place instead? Should there be something else?

5. The Relationship between Parents and Nursery Staff; trying to 'get on the same page' 10 minutes

Talk about empowerment/disempowerment. Are they aware of times when they feel disempowered? How can we encourage empowerment? Do parents need professionals to be the experts at first? What do staff feel about this?

Other areas to discuss which emerged from the data but which will benefit from further exploration: 10 minutes

No fathers took part in whole interview. How do fathers conceptualise their child's development?

Next Steps – 10 minutes

Is it always important to have shared understanding? Can we recognise different conceptualisations and still move forward in terms of promoting child's development?

Sameroff refers to the 3 Rs of intervention; remediation, re-education and redefinition. What do you think? What will help you to understand a child's progress? How can we work together etc? What have they learned as a result of this discussion? What has surprised them? What will they take away that is positive? What should we be doing differently to support children's progress?

APPENDIX 5.2. Hand-out of Themes for Focus Group Participants

RESEARCH PROJECT FOCUS GROUP

The Development of Young Children with Learning Difficulties

Parents and Staff Views
Themes for Discussion

1 SOCIETY INFLUENCES HOW WE THINK ABOUT A CHILD'S DEVELOPMENT

We tend to think of children making progress in a linear fashion

2 UNDERSTANDING THE CHILD IS A LEARNING PROCESS

Learning about a child's strengths and difficulties, and about his or her diagnosis can be a challenge but leads to a better understanding of their needs

3 THINKING ABOUT PROGRESS DIFFERENTLY

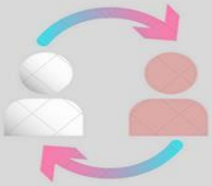
Children with learning difficulties don't always achieve typical milestones in the expected order.

4 FOCUSING ON THE 'BASICS'

Communication is the key focus for progress. Independence skills are very important too.

5 THE RELATIONSHIP BETWEEN PARENTS AND NURSERY STAFF

Good relationships can be empowering. What can we do do help parents and staff 'get on the same page'?



Kirstie Rees kzrees@dundee.ac.uk/kirstie.rees@slcpsych.org.uk

APPENDIX 6. Data Reduction and Analysis Process

Appendix 6.1 Example of Data Reduction and Analysis Process

- Manual transcription of interviews
- Reading/re-reading of data
- Textual analysis and initial noting (column 2) electronically. Analysis moves from left to right in table (Appendix 6.2)
- After initial reading, descriptive and linguistic comments and conceptual comments were made. Note of similarities/discrepancies were made in column 3.
- More conceptual comments/ possible themes noted in final column
- Further re-reading of whole interview and sections of interviews
- Discussion of these in supervision
- Return to all date to reduce data to main themes'
- Themes established within data from one participant at a time
- Themes then written on post its and presented visually; a further search for patterns across transcripts;- further reduction and clustering and identification of themes across all interviews
- Main themes were typed in a table – with examples of each from each participant then pasted into correct column in table (Appendix 6.3).
- Themes are then read and analysed to highlight connections and to identify superordinate themes and subthemes. Post its used again to aid this process.
- Identification of times when participants demonstrate polarised views of the same theme
- Data then entered into NVivo with themes with identified themes to enable numeration of the naming themes. This is sued as a means of corroborating or disconfirming identified themes
- Themes /subthemes presented on a diagram with some examples of quotes
- This informed the Analysis section of the thesis.
- The themes are depicted visually on an infographic and presented to the two focus groups to enable participants to confirm/reject chosen themes (Appendix 5.2)
- Focus groups were transcribed and analysed using the same method as employed with individual interviews.
- This time, the emergent themes form the interviews are used as a basis for themes. After the data reduction and analysis process, there was a further revision and rewording of original themes to reflect the contents of the focus group. These changes to themes are reflected in the final diagram depicting the superordinate themes, main themes and subthemes (Diagram 2).

Appendix 6.2. Examples of Manual Data Reduction Process Initial Coding

Transcript	INITIAL CODING	FURTHER REFLECTION AND CONCEPTUAL CODING
Yeah. I think like at first, it took him so long to even make eye contact or to talk to you, I 'm thinking; how severe is this going to be? But I think, you get more and more relaxed as you go on. I don't know if its just 'because they're not a baby anymore and you just feel like .. or you don't have a choice in it but.. we've always.. I've known parents who are still in denial about like their children having autism and I'm just.. on the group that we done More than Words.. we're all on a page together, a private page and the woman's always posting links to say like how to cure you're child and I'm like (tuts) I can't deal with things like that because we've actually dealt with Joe's diagnosis really, really well but you just need to, you just need to go with it .. there's no . there's point sitting stressing about something that you can't fix or change And Everybody has an opinion. And I know, myself, I'm quite a loud person, I'm quite confident when I'm talking to people and things like that but see when it comes to other people's children, even when my friends ask	Mum was concerned his difficulties were going to be more severe at the beginning You get **more and more relaxed** as you go on if you don't have a choice Can't deal with mums who are looking for a cure – we've dealt with his diagnosis **really really well** There's no pint stressing about something you can't fix or change Critical of another mum who is promoting the possibility of the child being 'fixed. She understands her son's needs. But is she accepting? Everyone has an opinion/Always people making comments He doesn't have a sticker on or badge – he looks the same as everyone else	Change in views – relaxed as his development – but words don't reflect that she is at ease. Hides true feelings; puts up shield You don't have a choice- puts up 'emotional shield' 'you just have to get on with it' – no choice – therefore lack of control? Resignation? Repetition to indicate **emotion**: you just need to' you just need to..? **Lack of power – control** – others in 'normal' world all have a view Sense that all others have a negative view- her versus the world Sense that she is constantly trying to present herself in a certain way; confident; accepting of needs (**Hiding her true emotions**?)

advice, I never give them advice, because I know they're not going to use it or will they be offended or..? I just say nothing. But I, there is always people making comments...and that's the thing he doesn't have a sticker on him or a badge to say and he looks the same as everybody else. K: Yeah, that's right L: I think before I used to be more worried about other people's opinions when you were out people would always.. because he does this high pitched scream a lot and it tends to be more when he's happy but see now, I'm just like 'let people look; let people make comments' because you can't challenge every single person who's going to make a comment about your child. K That's right, yeah, um that's hard L:You just have to grow a thick skin, K:And that's hard because sometimes you can do that, and So, yeah, you just got to.. And is anything preventing Joe from making progress. Do you think there's anything that should be in place or you would like..? I think the hardest thing is he has erm ..... one of the members of staff who didn't have a group who looked after him but obviously there's not just now so when he's getting the whole free play for basically three hours well three and a half hours because he start at half eight.. it's hard.. but it's very very hard to get somebody in to help.. and that was my huge worry about moving him into the 3-5s room coz I though he's not going to get an auxiliary..	Difference not noticeable physically – harder because she has to explain it? Let people look; let people make comments of Can describe and understand the function of atypical behaviours Develops a 'thick skin' Repetition – let people look; let people… You can't challenge every single person Used to be more worried about people's opinions Now she is let people look let people make comments You have to grow a thick skin – metaphor	But he IS different – more difficult because she ha to **explain the difference to others** Acceptance, resignation or defiance of the situation? **Emotional barrier again** In doeth knowledge of his communication, **atypical development** (Mum understands this; does she then accept it?) **Emotional challenge – defensive shield ; has to put up barrier to world; role reduced** Sense of mum versus the world – difference versus the norm? isolated from others She has **changed** about how she regards his development Again – she is shielding herself and Joe from the negativity of others Emotional impact on Joe and mum of **transition**

he's not going to get a one to one.. and he did, his transition took about three months.. it was really hard, and we just decided just to do it . He was upset going between two rooms and he didn't really want the big room, but we've just had to do it.. but I think that is the hardest . but I think the now, because it's the holidays, its much quieter but when it goes back to full numbers again.. I don't really know .. There'll be a lot of new faces.. there's a lot of new staff in the nursery as well in the last few months Is that right?	Huge worry repetition – its hard, very, very hard – extent of her anxiety about this Worry about ASN support – repetition again 'he's not going to get one..' Transition – use of education 'jargon Repetition of hard - Room is quieter – when it goes back number rise	Motherhood – treated differently – people can offer advice – because her child has a disability **REDUCED STATUS AS A MUM** Feels she shouldn't stress about something she can't change Difficulty again – emotionally for Joe Reference to **inadequacy of environment** at nursery –numbers , and also level of support required Looks the same as everyone else so she must explain his needs **Emotional – upset – anger**

Appendix 6. 3 Examples of Manual Data Reduction Process Reduction of Themes across Interviews

Themes from parent interviews	Emily	Maddie	Olivia	Joe	Tom	Leah
Learning process **For Parents**	Had to seek it out at first; only written info	Take the info they need at that present time – don't project Has changed- at first tried to get her to do things before she had mastered earlier skills Doesn't gauge development now	Mum highlights the fact that she knows her well and can understand her Mum has accessed loads of courses; this has	Concerned his difficulties were going to be more severe at the beginning – getting more relaxed as time goes on	Limbo – aiming for diagnosis Asking questions about school – uncertainty about what he will be doing there A lot of uncertainty about what he will be like in the future Sense of not knowing what they should be	Sought diagnosis had to keep seeking out professionals Seeking out info on google all the time tortured her _ remember thinking I'm losing the plot here Felt she was going nuts

		Was upset and distressed It took me a long time to get my head round it Scored out milestones in red book – symbolic You need to understand it yourself – did a lot of research Readjustment	helped her put strategies in place		doing or accessing at the beginning As a parent, how do you know what you should be doing, looking for if nobody's there to tell you what you should be looking for Change – at first, they were wanting everything to happen quickly – now they are more relaxed – understand it must be at his pace Thought when things were in place, his progress would move on quickly – now realise this is not the case	Reading has